
NURTURING CHANGE

Working effectively with high-risk women
and affected children to prevent and reduce
harms associated with FASD

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Breaking the Cycle



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PURPOSE OF THE MANUAL

The manual was written to enhance the skills of service providers working in prenatal and early childhood settings in Canada to:

- Engage and support pregnant women who use alcohol or other substances;
- Identify and support children who may be affected by prenatal alcohol exposure, and their families.

The curriculum was developed for service providers in Health Canada’s Canada Prenatal Nutrition Program (CPNP) and Community Action Program for Children (CAPC).¹ It builds on a previous a study² that confirmed the value of locating FASD-related activities within CPNP and CAPC projects. The non-judgmental, respectful and culturally sensitive environments cultivated by these projects present a milieu that effectively engages high-risk pregnant women and families, and situates them well to address the complex issues that usually arise when addressing impacts of alcohol and other substance use during pregnancy or in early childhood.

In addition to CPNP and CAPC providers, we hope that the curriculum will be of use to all community-based practitioners working in prenatal and early childhood settings that have contact with women, children and families who may be affected by prenatal alcohol or other substance use.

It is important to note that this curriculum assumes a basic foundational knowledge of FASD and related issues, and offers applied strategies and approaches for serving women, children and families who are affected by prenatal alcohol or other substance use.

The training manual is also available electronically at www.ccsa.ca/fas and www.mothercraft.org

¹ See Appendix B for descriptions of Health Canada’s CPNP and CAPC programs.

² Leslie, M., & Roberts, G., Enhancing Fetal Alcohol Syndrome (FAS)-related Intervention at the Prenatal and Early Childhood Stages in Canada. Ottawa: Canadian Centre on Substance Abuse, 2001.

OVERVIEW OF THE MANUAL

The curriculum presents an integrated framework for understanding and responding to FASD issues

..... through the **prevention** or reduction of harms associated with alcohol or other substance use in pregnancy. Emphasis is given to the fact that pregnant women who use alcohol are also “subject to other adverse conditions that are strongly related to their use, including: poor nutrition, poverty, tobacco use, illicit drug use, violence, history of obstetrical problems, and lack of prenatal care, among others. Thus, FAS is not simply an issue of alcohol abuse but a complex issue rooted in the underlying social and economic conditions which influence all aspects of maternal and child health”.³

.....through the timely **identification** of children who may have special needs stemming from prenatal alcohol exposure. The importance of involving families (biological, foster and/or adoptive) in the process towards understanding the child’s particular vulnerabilities and strengths is emphasized.

.....through the **assessment and diagnosis** of children who have been identified with challenges stemming from prenatal exposure to alcohol. While this curriculum does not focus on the activities of assessment and diagnosis, it does emphasize the important role of the parents and caregivers in this process. Respectfully and sensitively engaging pregnant women who use alcohol in the process of planning and information-sharing around their infant-to-come is critical to accurately assessing and understanding the child’s needs – at birth, and throughout his/her life – and, most importantly, to acquiring an accurate diagnosis.

.....and through the establishment of appropriate **interventions** which capitalize on strengths, and support special challenges. Accurate assessment and understanding of the child’s strengths and vulnerabilities result in the opportunity to optimize outcomes and prevent the development of secondary disabilities in children who are inaccurately understood and responded to throughout their lives.

When this continuum of caring is interrupted or fragmented, the likelihood increases that the affected child will not be identified, assessed, and receive appropriate intervention. This, in turn, increases the risk for the development of secondary disabilities, which include mental health problems, substance use, victimization, criminality, trauma and unplanned pregnancy.

³ Canadian Centre on Substance Abuse (CCSA) National Working Group on Policy, 1994. *Fetal Alcohol Syndrome: An Issue of Child and Family Health. A Policy Discussion Paper* <http://www.ccsa.ca/pdf/ccsa-004978-1994.pdf>

The curriculum describes the application of the Transtheoretical Model of Behaviour Change (Stages of Change)⁴ and Motivational Interviewing⁵ as approaches for working both with pregnant women who use alcohol or other substances, as well as with families (biological / foster / adoptive) of children who are or may be affected.

Although the manual focuses on alcohol use, the strategies and approaches described in Sessions 1-4 [Day 1] can be applied to support women struggling with alcohol and/or other substance use. Sessions 5-8 [Day 2] however, focus specifically on identification, intervention and support for children affected by alcohol, and their families.

⁴ Prochaska, J. and C. DiClemente (1984). *The Transtheoretical approach: Crossing traditional boundaries of therapy*. Homewood, Ill., Dow Jones-Irwin

⁵ Centre for Substance Abuse Treatment. (1999). *Enhancing Motivation for Change in Substance Abuse Treatment: Treatment Improvement Protocol (TIP) Series 35*.

Rockville, MD: US Department of Health and Human Services.

[Online] Available: <http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat5.chapter.61302>

USE OF THE MANUAL

This training manual can be used for self-study or in the delivery of training sessions. The training is designed to be delivered in two days, and it contains 8 sessions:

DAY 1: Engaging and supporting pregnant women who use alcohol or other substances

Session 1: Reflecting on Service Providers' Values and Beliefs

Session 2: Understanding Women's Alcohol and Other Substance Use

Session 3: Motivational Counselling Strategies

Session 4: The Stages of Change Model and its Relationship to Client Motivation

DAY 2: Identifying and providing effective interventions for children affected by prenatal exposure to alcohol or other substances and their families

Session 5: Identifying Children Affected by Prenatal Exposure to Alcohol

Session 6: Supporting Families Affected by FASD

Session 7: Interventions to Support Children with FASD

Session 8: Advocating for Children and Families Affected by FASD

Each session includes learning objectives and key questions that will be answered through the content material delivered in that session. Learning activities are in the form of case studies, role-play exercises, small and large group discussions, worksheet exercises and training on tools.

SAMPLE TRAINING AGENDA

Day 1:

0845: Introduction
0900: Session 1
1030: Break
1045: Session 2
1215: Lunch
1315: Session 3
1445: Break
1500: Session 4
1625: Wrap Up of Day 1
1630: Adjournment

Day 2:

0900: Session 5
1030: Break
1045: Session 6
1215: Lunch
1315: Session 7
1445: Break
1500: Session 8
1620: Day 2 and Workshop Wrap Up
1625: Workshop Evaluation
1630: Adjournment

RECOMMENDATIONS FOR TRAINING

1) **Community readiness:**

Sensitivity to issues related to culture, language, personal/community history and its relationship with alcohol use and pregnancy, access to resources, and community / personal readiness to change is critical. Trainers should adjust the curriculum to meet the needs of communities.

2) **Composition of the training audience:**

Communities should be encouraged to invite participants that reflect a broad cross-section of relevant community interests. Cross-sectoral representation among training participants facilitates community development, partnership linkages, and implementation of training knowledge.

3) **Trainer qualities**

The design of this manual is based on the belief that the best trainers:

- are passionate about their subject;
- espouse the values and beliefs described in the manual;
- have had personal or professional experiences affording them anecdotal information that brings the subject matter to life;
- are able to update their training materials as new information becomes available;
- enjoy and are comfortable speaking to groups as a trainer;
- can organize presentations based on the needs of their audiences;
- are able to support individuals around personal issues that arise during the training.

Remember: The first responsibility of a trainer or intervener is *to do no harm*. Information regarding FASD is complex and needs to be delivered accurately with respect and care by experienced professionals. Those considering delivering this information need to be clear on their professional competencies and apply the Code of Ethics for their profession to ensure they are able to present this information in a fully helpful way.⁶

⁶ Aboriginal Nurse Association of Canada (1997). *It Takes a Community: A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects*. Ottawa: Minister of Public Works and Government Services Canada

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SESSION 1:

REFLECTING ON SERVICE PROVIDERS'
VALUES AND BELIEFS

Session 1: Reflecting on Service Providers' Values and Beliefs

Objectives/Outcomes

By the end of this workshop session you will:

- increase your awareness of personal beliefs that support non-judgmental, respectful, and collaborative relationships with pregnant and parenting women who are substance-involved, and;
- build on your repertoire of responses that foster a non-stigmatizing relationship with, and facilitate change for, substance-involved pregnant and parenting women.

Key questions

1. What is my role in supporting change for substance-involved pregnant and parenting women?
2. Do I have attitudes, beliefs, or a counselling style that supports the development of a non-stigmatizing relationship with substance-involved pregnant and parenting women?
3. Can I resist the temptation to focus on long-term goals and, instead, consider small steps the woman can take?

Learning Activity #1: Understanding Attitudes

Attitudes are a result of information, personal experiences (past and current), societal messages, and personal values. Validating feelings is a first step towards changing attitudes. These guiding principles are important when identifying and supporting substance-involved pregnant and parenting women:

- Respect
- Understanding
- Compassion
- Hope
- Responsibility

The Learning Activity

1. Write a word on a piece of paper that describes a feeling a substance-involved pregnant and parenting woman might have. You may write as many feeling words as possible using a separate piece of paper for each, and placing each into a bowl or a bag.
2. The container is then passed to each member of the group. Each person draws 2 - 3 pieces of paper. As each piece of paper is drawn, the participant states the feeling word and the facilitator writes the word on the flip chart.
3. When all the words have been noted, the facilitator will lead a group discussion about what might lead the pregnant or parenting woman to have these particular feelings.

Learning Activity #2: Clarification of Personal Beliefs

The purpose of this exercise is to examine our personal beliefs and understand how our beliefs can affect our interactions with clients.

Participants should not feel pressured to disclose personal information. Rather, the point of the exercise is to recognize how our personal beliefs can impact on interactions with pregnant and parenting women to either facilitate, or create barriers for, change.

The Learning Activity

The following questions will be discussed:

- **Are there personal beliefs or experiences that could prevent** service providers from remaining non-judgmental, empathic, respectful, and supportive when they encounter a substance-involved pregnant or parenting woman?
- **What ways could service providers overcome personal beliefs** about a woman's need to change her substance use quickly?
- **How could service providers support her self-determination** and her plans to change at her own pace in a non-coercive and caring fashion?
- **What helps me stay hopeful** while finding ways to encourage hope in a substance-involved pregnant or parenting woman?

Service Providers' Values and Beliefs

Our role as service providers is critical. If we can support a pregnant woman in her attempts to change, this is a key factor to her success. Our approach is a key to whether a woman will change her substance use. The relationship we develop with her can be as important as the woman's personal characteristics and behaviour. When women are asked about the kinds of approaches that have been the most effective for them, a supportive, non-stigmatizing relationship with a service provider is among the most helpful and effective. On the other hand, one of the main barriers to seeking help and support is the fear of being treated prejudicially.

Because of the urgency we may feel to support substance-involved pregnant women to make changes in their substance use behaviour, we may be tempted to rush women into actions that they may not be ready to undertake (for example, into immediate abstinence). If we press women to make changes that are impossible for them, they will often perceive that we don't understand their circumstances or their abilities. Pressure to change quickly also has the potential to set up failure and shame for the woman. Instead, help her to identify manageable small changes that can occur over time.

1. Frame straightforward questions

Some service providers don't ask pregnant or parenting women questions about substance use because they fear the woman will get angry or they don't know what to do next if she confirms substance use. Some effective strategies to encourage an open response from the woman include:

- Ask questions about substance use in a matter-of-fact way - try to be calm and direct, straightforward, and non-judgmental;
- Strive for a neutral response and try not to feel overwhelmed;
- Think of a range of possibilities and suggest some small steps a pregnant woman can take to make change; be aware that sometimes these small steps are all that's needed.

Our attitude will usually determine a woman's reaction. If she perceives us to be fair and open, it is more likely she will be open. Here is an example of how to phrase a question about substance use.

Do say:

Can you see yourself making any changes in your substance use? What would they be?

Don't say:

So your next step should be to quit using substances.

Here are some general approaches for asking questions:

- When you ask about sleeping patterns and eating habits, also ask about substance use, since these questions belong within the context of overall health;
- Open-ended questions (*How much do you use?*) are always better than closed ones (*Do you use substances?*);
- If the woman says she uses substances, then ask other probing questions, such as: *How much do you use daily or weekly? How long have you been doing this? and When was the last time you used?*

Questions asked as part of a series of general health questions will facilitate an on-going discussion with the woman. Be prepared with follow-up questions and refer as needed. **It's not up to us to make a diagnosis of substance abuse.** Instead, for example, refer to a local addiction counselling service that provides women-centred, holistic support for the woman⁷ or to the Motherisk telephone help line (1-877-327-4636).

2. Dispel myths

Many women are given the wrong information about the effects of alcohol and other drugs. This misinformation can come from anywhere - physicians, other helping professionals, friends, or family. For example, many women will say their friends or families told them it was OK to drink beer during pregnancy because it helps with breastfeeding later on. And their friends have the proof of their own healthy babies to show for it. It's important to understand this because it helps us adopt a less judgmental attitude. Pregnant women do not use alcohol because they are irresponsible. The fact is they might not have the right information. A key role for service providers is to provide reliable information and separate fact from fiction. Bear in mind that many women are given inaccurate information about substance use during pregnancy, either from professionals or from friends. Some strategies to help dispel myths include:

- Talk to the woman in a conversational, matter-of-fact way;
- Ask her what she's heard about substance use during pregnancy;
- Refer her to factual information from a credible source (e.g., Motherisk help line);
- Go slowly - it takes time for the woman to digest new information and to believe it.

3. Ask questions more than once

Sometimes helping professionals fall into the trap of asking questions about substance use only once; however, questions about use should be repeated. Some strategies to bear in mind include:

- Every interaction with a pregnant woman (regardless of whether or not she initially revealed it) should include questions about substance use;

⁷ The availability of women-centred addiction treatment programs varies greatly from region to region, and from community to community. For a database of addiction treatment programs in Canada, visit www.ccsa.ca

- Continue to frame the questions in a matter-of-fact way and within the overall context of her health;
- The non-judgmental approach is especially important for a woman who originally minimized her substance use - this woman needs to know you are always open and able to listen, if she decides to reveal her substance use later on in her pregnancy.

4. The service provider's role in change

The approach we take is one of the keys to whether a woman will change. Our approach is just as important as the woman's personal characteristics and behaviour. Our role in change is to:

- Increase her **self-efficacy**⁸;
- Help her internalize her **locus of control**⁹;
- **Use harm reduction** strategies whenever possible¹⁰;
- Focus on both mother and infant;
- Be sensitive to trauma issues.

Service providers are in a unique position to encourage change. Strategies that can be used to facilitate change include:

- Provide a lot of positive feedback for the woman's decision to seek care for herself and her infant; continue to make positive statements at each contact (her belief in her ability to make change is the best predictor of successful change);
- Highlight the woman's ability to make choices; this leads to higher self-efficacy and helps her believe the power to change is within herself - this is another effective tool in motivational approaches;
- Be non-judgmental - this means you listen attentively to the woman's concerns and refrain from negative comments and reactions;
- Encourage any small changes that reduce high risk behaviours;
- Talk about substance use **and** pregnancy or parenting concerns - pregnant women want to be treated as whole beings, not simply as pregnant women;

⁸ Self-efficacy: the belief that you can influence your own thoughts and behaviours; that you can make lasting changes, and therefore have more control over your life.

⁹ Locus of control: the extent to which people perceive outcomes as internally controllable by their own efforts and actions or as externally controlled by chance or outside forces; the belief about the amount of control a person has over situations in their life.

¹⁰ Harm reduction: involves supporting people in making whatever change is possible in their use of substances and/or in behaviour related to use, so that harm to themselves and to others is reduced¹⁰

- Be aware that her substance use may be functioning as a coping mechanism - many women with substance use problems have histories that include violence and sexual or physical abuse, especially those women who find it difficult to abstain from substance use;
- Address family issues and offer support to family members where possible.

Our Approach is a Key to Helping a Woman Change

The approach we take is one of the keys to whether a woman will change. Our ability to engage the woman in a supportive relationship can be just as important as the woman's personal characteristics and behaviour. Examine your personal strengths and potential biases to ensure that you develop with her a respectful and collaborative relationship.

SESSION 2:

UNDERSTANDING WOMEN'S ALCOHOL
AND OTHER SUBSTANCE USE

Session 2: Understanding Women's Alcohol and Other Substance Use

Objectives/Outcomes

By the end of this session workshop you will:

- gain an increased awareness of root causes of substance use in women and their interconnection with a variety of difficult life circumstances;
- increase your awareness of the effects of substance use on women's lives;
- be able to articulate a range of responses that will communicate understanding and encourage change.

Key questions

1. What is the role that continued substance use plays in the lives of pregnant and parenting women?
2. How can empathy be communicated when pregnant and parenting women continue to use substances?
3. What steps can I take to reduce the harm of substance use?

Understanding Women's Alcohol and Other Substance Use

Pregnant and parenting women use substances for varied and interconnected reasons. For many women, substance use helps them contend with difficult life circumstances such as a history of trauma (violence or sexual abuse), current domestic violence, poverty, or feelings of guilt, shame, and inadequacy. Substance use may be a regular part of their environment - their partners, friends, and family may all be substance users. Some women may also be physically dependent on alcohol or other drugs, which makes abstinence more difficult, especially within the short time frame of a pregnancy. Service providers need to address a pregnant and parenting woman's use of alcohol and other drugs. However, as much as possible, the range of issues that contribute to her substance use must also be addressed. Service providers must try to convey to women an understanding of the context of their lives. Service providers need to also try to communicate empathy for the difficult circumstances in which many women live. These circumstances mean that mutually determined, small goals are most feasible and can lead to positive change for many substance-involved pregnant and parenting women.

Pregnant and parenting women who use substances “do not do so because they are unaware of the public health message, or because they are indifferent to the potential harm to their fetuses. Rather, the contributing factors to substance misuse by pregnant women are complex and varied, and therefore call for services and programs which reflect this reality.”¹¹ There are a variety of circumstances that can impact on the lives of substance-involved pregnant and parenting women, including increased risk of depression, high levels of stress, low levels of social support, greater risk of domestic violence and histories of trauma, a greater likelihood of living in poverty, and partners, friends, and family who are substance users.

1. Understanding Consequences

Substance-involved pregnant and parenting women report that the biggest barriers to getting help are guilt, fear of being judged, and fear of losing their children¹². A woman might fear disclosing her substance use because she fears the involvement of child welfare services or having a child removed from her care. These barriers can lead to the woman providing “half-truths” to service providers and physicians, avoidance of prenatal care, and avoidance of addiction treatment. The consequences of these behaviours will often result in the woman's worst fear; that is, having her children removed from her care.

¹¹ Tait, C. (2000). *A Study of the Service Needs of Pregnant Addicted Women in Manitoba*. Winnipeg: Manitoba Health.

¹² Poole, N. and Issac, B. (1999). *Mothering and substance use: An exploratory research study on barriers and supports for women who are pregnant and parenting when accessing services for alcohol and other drug problems*. Vancouver, BC: BC Centre of Excellence for Women's Health.

She might feel **guilt**, thinking her substance use has harmed herself and her infant. Guilt can present as defensiveness, hostility, or resistance. It is very important not to increase her guilt, because guilt can lead to increased substance use, especially during pregnancy.

She might **fear for her physical safety** if she reaches out for help with an alcohol or other drug problem. This is a very realistic fear, as women who live with a violent partner are most at risk of injury or death immediately after they leave the situation.

She may be **overwhelmed by feelings of worthlessness and inadequacy**, which can produce inertia or low self-efficacy (i.e., she does not believe she is capable of changing her substance use).

She may be using substances as a **coping mechanism for dealing with trauma issues**. When substances are removed from her life, the woman's underlying issues, such as trauma, abuse, domestic violence, depression, or anxiety, might surface - so she feels overwhelmed or discouraged and continues to use substances to cope.

2. Supportive Steps

- **Explore the function substance use serves in her life.** Be prepared to address her needs if she quits her substance use. For example, she might use substances to cope with an underlying depression. So, before she quits using substances, supports must be in place to help with that.
- **Acknowledge the positive role substance use can play** in the woman's life, such as stress management, support in social interactions, and self-medication of trauma or abuse. Also, this will show the woman you are open and non-judgmental. It will also help her begin to examine her substance use.
- **Emphasize the benefits of any reduction in substance use.** For example, for pregnant women, it's never too late in her pregnancy to make small changes in her substance use. Provide her with ideas about how to make changes or shifts in her use.
- **Encourage any and all small changes** that reduce high-risk behaviours. Feel encouraged by small changes, not hopeless and discouraged in the absence of complete change.
- **Recognize the context of a pregnant woman's life.** Many pregnant women have stressful lives. It's not only substance use that affects the health of pregnant women and their children. Poverty, lack of food security, violence, and lack of opportunity and support all contribute to negative birth outcomes. If we communicate our understanding of her life, she is more likely to respond favourably to us.

- **Talk about both the mother *and* the baby.** Talk about both substance use *and* pregnancy concerns. Let her know that both she and the baby are important. But help her make a connection to her infant. Substance use can cause her to detach from the baby. A self-protective thought process takes over. She comes to believe that her substance use affects only her own health, not the baby's.
- **Avoid blame.** Many pregnant women who use substances *intend* to change, but lack the necessary skills. Some service providers might misread this as lack of intent. Instead, we need to work with the woman to find the necessary skills.
- **Be sensitive to trauma issues.** Many women with substance use problems have histories of violence and sexual or physical abuse, especially those women who find it difficult to quit their substance use.
- **Explore the woman's values about change.** We cannot assume a pregnant woman's values about the benefits of change are the same as ours. We might believe change is positive and necessary, especially because of the baby. We must not impose our reasons for change on her.
- **Acknowledge the social context of substance use.** Family, friends, and community norms all have an impact on the way a pregnant woman uses substances. If she changes her substance use, her whole life can potentially be disrupted. It's normal for people to fear change and expect life to be worse afterwards.

There are a variety of reasons why pregnant and parenting women may feel unable to make changes in their substance use behaviour. Many live in very difficult life circumstances with little or no support. The consequences of change can be profound and not necessarily positive. Empathic service providers can take small steps that will have a significant impact on producing change.

Learning Activity #3: Understanding Women's Substance Use

The purpose of this learning activity is to provide an opportunity to confirm and extend our understanding of the root causes of women's substance use.

The Learning Activity

The following questions will be discussed in small groups and fed back in a large group discussion.

1. What are the reasons for women's substance's use?
2. What are barriers for pregnant women using substances to access supports around their substance use and pregnancy?
3. What are effective approaches to overcoming these barriers?

Recommended video: “*Different Directions: Early Interventions in FAS*”¹³. This 15-minute video involves interviews with women and service providers who discuss reasons why women use, barriers for accessing help, and effective approaches for support. It may be screened prior to the small group exercise to stimulate discussion.

¹³ Order *Different Directions: Early Interventions in FAS*” produced by Breaking the Cycle and Ontario's North for the children. Phone 705-567-5926 or FAX 705-567-5925

SESSION 3:

MOTIVATIONAL COUNSELLING STRATEGIES

Session 3: Motivational Counselling Strategies

Objectives/Outcomes

By the end of this session you will:

- have an increased awareness of motivational counselling strategies.
- have an increased capacity to use motivational counselling techniques that will support pregnant women to address substance use issues.

Key questions

1. What are the basic beliefs of motivational counselling?
2. What are the basic principles of motivational counselling?
3. What are the basic strategies used in motivational counselling?

Motivational Counselling Strategies

Motivational counselling has been shown to be very effective when dealing with anyone with a substance use problem, including pregnant and parenting women. The technique places the onus for developing the motivation for change equally upon the service provider and the client herself.

There are a variety of specific strategies that can be used within the framework. The key is understanding three primary concepts:

1. Empathy, not guilt or fear, will provide the appropriate atmosphere in which change will occur;
2. Self-efficacy is the foundation upon which change rests; and
3. Resistance to change is often a creation of the interaction between counsellor and client.

Within motivational strategies, harm reduction (or small steps to change) can be seen as a legitimate option wherein women can be encouraged to make incremental changes that will eventually produce lasting change.

Motivational strategies have been developed primarily by Dr. William Miller¹⁴. Within this framework, motivation is not seen as a behaviour trait or personality characteristic of the individual. Instead, **motivation is seen as a product of the interaction between client and service provider.**

Motivational approaches:

- **are interactive** and based on the belief that change takes place within the relationship between the service provider and the woman;
- **place responsibility for change on the service provider and the woman;**
- **are centred on the pregnant woman and are empathic.** The service provider will always avoid shame, blame, scare tactics, or guilt and instead focus on communicating support and understanding;
- **avoid labels**, such as *alcoholic* or *drug addict*. Labels can be stigmatizing, shaming, or prejudicial, and, in fact, may not realistically refer to the woman's situation. Rather than using the term, "substance abuse" it is always better to refer to *substance use* by women or *substance-involved* women;
- **reduce resistance** by meeting resistance with reflection rather than confrontation.
- **foster a commitment to change** and brings the woman to greater awareness of, and responsibility for, her substance use;

¹⁴ Centre for Substance Abuse Treatment . (1999). *Enhancing Motivation for Change in Substance Abuse Treatment: Treatment Improvement Protocol (TIP) Series 35*.

Rockville, MD: US Department of Health and Human Services.

[Online] Available: <http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat5.chapter.61302>

- **emphasize personal choice** regarding substance use, and personal control over decisions, by providing a range of possible alternatives for change;
- **negotiate** goals between the woman and the service provider. A range of options for change is presented to allow her to select the best options for herself;
- **remove barriers to change** by providing child care, transportation, and any other accessibility issues a woman might face;
- **accept relapse** as part of the process of change.

Here are the **basic principles** of motivational approaches:

1. **Express empathy** through reflective listening. Use gentle persuasion but understand that the final responsibility for change is up to the woman. Communicate respect for and acceptance of the woman's feelings.
2. **Avoid argument.** Direct confrontation can turn into a power struggle. Instead, work together to negotiate a change plan. Be non-judgmental and supportive. Listen rather than tell.
3. **Roll with resistance.** Don't oppose it. This leads to argument or defensiveness. Adjust to resistance by changing your strategies. There are many different types of resistance that are sometimes easy to identify, but more difficult to identify at other times. Pregnant women who are resistant might argue, interrupt, deny, or ignore.

Try to view resistance as an opportunity - to keep the woman involved, to engage her in the process of change. Resistance is counter-productive. It causes people to feel angry, stop listening, or drop out. **You can decrease resistance if you:**

- express empathy
 - remain non-judgmental and respectful
 - encourage the woman to talk and stay involved with you
 - emphasize her personal choice and control
4. **Develop discrepancy** between the woman's goals and her current behaviour. Her ability to recognize this contradiction is a powerful motivator to change. Reflect the contradiction between her goals for the future and her current behaviour. Help her recognize the conflict between where she is now and where she hopes to be.

Do say. *On the one hand, your long-term goal is to go back to school and finish your college degree. But on the other hand, you say that if you've been drinking, you can't get up in the morning.*

Don't say. *You want to go back to school but you drink every day - there's no way you can manage a course load until you stop drinking.*

5. **Support self-efficacy.** Focus on the woman's strengths. Support the hope and optimism needed to make change.

Encourage her belief in her ability to change or *self-efficacy*. It is the belief that you can make lasting changes and therefore have more control over your life. Encourage any small reduction in high-risk behaviours, such as substance use. Help her take credit for those changes. Emphasize and reinforce any small steps the woman is able to make towards change.

6. **Use gentle strategies.** Maintain an empathic and non-judgmental approach to the woman's perception of her situation. Keep her involved with you. Use these strategies:

- express concern
- establish a trusting relationship
- ask permission
- keep the door open

Do congratulate the woman for her attendance. *Thank you for making the effort to come in today. I know it must have been difficult to talk about these things.*

Don't rush the woman to solutions. *So you're here to find out how to quit drinking.*

Ask questions about her life in a direct but non-threatening way. Remember: many factors can contribute to negative birth outcomes.

Do ask. *Can you tell me about any time in your life someone hit you, shouted at you, or harmed you in any other way? How often does this happen?*

Don't ask. *Does anyone abuse you?*

7. **Emphasize the benefits of any reduction in substance use.** It's never too late in her pregnancy to make small changes in her substance use. Provide her with ideas about how to make changes or shifts in her substance use.
8. **Acknowledge the positive role substance use can play** in the woman's life, such as stress management, support in social interactions, and self-medication of trauma or abuse. Also, this will show the woman you are open and non-judgmental. It will also help her begin to examine her substance use.

Do ask. *What are some of the benefits you get from drinking?*

Don't ask. *Why do you continue to drink when there are so many negative consequences?*

9. **Be straightforward and matter-of-fact.** Don't alarm the woman about her substance use, but provide factual information about the range of effects substances can have. Some statements you can make *in a neutral, non-judgmental tone of voice* are:
- *It's up to you what you're going to do about your substance use. No one can decide this for you.*
 - *No one can change your substance use for you. Only you can.*
 - *You can decide to go on using substances or to change.*
10. **Avoid blame.** Many pregnant women who use substances *intend* to change, but lack the skills necessary to make change. Some service providers might misread this as lack of intent. Instead, you need to work with the woman to find the necessary skills.

Here are the **five basic strategies** to use in motivational approaches:

1. **Ask open-ended questions.** Open-ended questions cannot be answered with a single word or phrase. For example, don't ask, "*Do you like to drink?*" Instead, ask, "*What are some of the things you like about drinking?*"
2. **Listen reflectively.** Show you have heard and understood the woman - repeat in your own words what she has said.
3. **Summarize** periodically what she has said up to that point. It allows people to hear something three times: the woman says something, you reflect it, and then you summarize it later. Summarize at various intervals throughout each interaction with the woman.

Do say. *So let me summarize: when you first came in, you were wondering if you could be successful with the changes you're contemplating. As we talked, you told me that over the last week, there have been several days when you didn't drink. You said those days really made you feel more confident in your ability to continue to cut back on your drinking. Am I understanding you correctly?*

Don't say. *I knew you could stop drinking. Good for you. Let's try to go a whole week next time.*

4. **Affirm.** Support and comment on the woman's strengths, motivation, intentions, and progress.

5. **Elicit self-motivational statements.** The woman herself must make the statements about personal concerns and intentions to change. Don't say it for her. Try to encourage her to make these statements. It's crucial for people to express their motivations in their own words. Many service providers have a tendency to do this for the woman. Remember: people retain what **they** say, not what **you** say.

Do say. *What makes you think that if you decide to make a change, you could do it?*

Don't say. *I know you can quit drinking. I really believe you can do it.*

Understanding resistance

Some service providers think resistance is a sign of defiance or non-compliance. But in motivational approaches, the viewpoint towards resistance is very different. In motivational approaches, resistance is not seen as a sign of defiance, but as a signal for us to change strategies.

From the pregnant woman's perspective, resistance can signal that:

- she views the situation differently from you;
- she feels helpless to change or is in conflict about change;
- she perceives you have taken away her control and personal choice in decision-making

From the service provider's perspective, resistance can signal that:

- **you need to slow down.** You have encouraged her to change too quickly, misjudged the importance of change to her, or over-estimated her confidence in or her readiness to change;
- **you have been judgmental** or have labelled the woman (for example, *an Alcoholic* or *in denial*);
- **you need to roll with resistance** and avoid argument;
- **you need to listen more carefully** or change direction.

Remember: Resistance can be increased or decreased based on what you say and do.

Learning Activity #4: Role Play – Talking with Jenny or Talking with Beth

The purpose of this learning activity is to provide an opportunity to reflect on the beliefs and principles of motivational counseling through the application of strategies in a role play exercise.

The facilitator will ask you to gather into small groups of three. Select **one** of the two case scenarios below to work on, based on the area of interest of the group. *Talking with Beth* focuses on working with a pregnant woman using alcohol; and *Talking with Jenny* focuses on working with a child who may be affected in a childcare setting.

Case Scenario I: Talking with Beth

Beth has been coming to your prenatal program sporadically for about two months. She is four months pregnant. Her first baby was taken into care about a year ago because she was drinking heavily. She comes to your program because she has heard good things about it in the community and she really needs the milk coupons you provide. She is also very interested in the food and clothing your program provides. Beth's partner is not that supportive because of Beth's previous experience with professionals.

Beth reports seeing her doctor regularly, she has attended most prenatal classes and has started to purchase things she needs for the baby. She is willing to discuss some life issues, but not others. Beth has never had any treatment for alcohol use. Beth says she is not interested in addictions "treatment" but would like more parenting supports.

Because of Beth's history, you are wondering about her current alcohol use. How will you explore this with Beth?

Reflecting on the beliefs, principles and strategies of motivational counseling, role play a conversation with Beth. Take turns being Beth, the prenatal outreach worker and an observer. The role of the observer is to provide feedback to the prenatal outreach worker regarding her/his counseling technique.

Case Scenario II: Talking with Jenny

Angela is a very quiet little girl, who plays by herself much of the time at day care. She does have unexpected, and prolonged temper tantrums at times, especially when things get busy at the centre, when she is tired, or during transitions from one activity to another. Daycare staff members have some concerns about Angela's development. Her language is somewhat delayed, and she often has trouble following directions. She often waits and watches what the other children are doing before responding to instructions. She tends to play with toys in a way that would be expected from a younger child.

Angela's mother, Jenny, is 21 years old. Day care staff know that Jenny did have difficulties with alcohol as a teenager, and that Angela was in a foster home for a while when she was an infant. Jenny works hard to care for Angela, and appreciates helpful suggestions from day care staff when they find ways of managing Angela's behaviour and share these with Jenny.

The day care staff have recently received some training in identifying children with prenatal alcohol exposure, and Angela is one of the children in the centre that staff have wondered whether this is a factor in some of their concerns.

Reflecting on the beliefs, principles and strategies of motivational counseling, role play a conversation with Jenny. Take turns being Jenny, the daycare worker and an observer. The role of the observer is to provide feedback to the daycare worker regarding her/his counseling technique.

Questions for debriefing in small groups and in large group discussion

1. Give each other feedback on your experience of **being Beth or being Jenny**.
 - What did Beth and Jenny find helpful? What was not helpful?
 - How did you feel as Beth or Jenny?

2. As the prenatal outreach worker, how did you feel about exploring Beth's current alcohol use? As the day care staff how comfortable did you feel discussing your concerns with Jenny?
 - In both scenarios, did you experience any feelings or reactions about drinking during pregnancy?
 - Did your feelings affect your discussion with Beth or Jenny?
 - Are there ways for you to explore your feelings and reactions within your program?
 - What further skills would you like to develop?

3. What did the observer notice as s/he watched the conversation between Jenny and the day care worker or between Beth and the prenatal outreach worker?
 - What helpful suggestions does the observer have for the day care worker or prenatal outreach worker?
 - What did you as the observer learn to help in your own skill building?

Conclusion

Motivational counselling strategies can be used at each stage of change with substance-involved pregnant and parenting women. The responsibility for change rests jointly with the service provider (and their ability to develop a mutually respectful relationship) and the woman. Your goal is to increase a woman's motivation to make change while reducing her resistance. Expressing empathy and supporting self-efficacy are key elements in the process.

SESSION 4:

THE STAGES OF CHANGE MODEL AND
ITS RELATIONSHIP TO CLIENT
MOTIVATION

Session 4: The Stages of Change Model and Its Relationship to Client Motivation

Objectives/Outcomes

By the end of this session you will:

- increase your awareness of the five stages of change (precontemplation, contemplation, preparation, action, and maintenance) and their connection to relapse;
- be able to articulate service provider strategies that can be used to motivate substance involved women to take action;
- understand how to complete a Functional Analysis;
- understand how to complete a Decisional Balance Index (DBI).

Key questions

This session will provide you with answers to the following questions:

1. What are the five stages of change?
2. What is the role of service providers at each different stage of change?
3. Which motivational counselling approaches are appropriate for substance-involved pregnant and parenting women?¹⁵
4. What role can a Functional Analysis play in motivating a woman to change?
5. What role can a Decisional Balance Index (DBI) play in motivating a woman to change?

¹⁵ Because the majority of women in CPNP and CAPC projects are in the precontemplation and contemplation stages of change, we have provided more detail around the strategies and tools to be used in these first two stages. Women in preparation, action and maintenance stages of change are often also involved in the addictions treatment system, and therefore the role of community-based providers includes collaboration with providers in that system.

The Stages of Change Model

In early approaches to substance use counselling, people believed that clients display various degrees of denial of their substance use problem or its severity. More recently, a different viewpoint has been developed, in particular through the work of Prochaska and DiClemente¹⁶ in what is known as the Transtheoretical Model of Behaviour Change or Stages of Change Model. Service providers will come into contact with a substance-involved pregnant and parenting woman in various “stages of change”. Depending upon her stage of change, there are implications for her readiness to engage in the helping process. Her stage of change also has obvious implications for the level of motivation she brings to the counselling or helping situation. Contemporary helping approaches do not see the client as “unmotivated”, “in denial”, or unable to be supported if she is not highly motivated in the initial stages of counselling. In fact, this is commonly the case, so the emphasis is on determining a woman’s stage of change, understanding techniques for dealing with women in each stage, and applying motivational counselling skills appropriate to the woman’s stage of change.

Overview

The Transtheoretical Model of Behaviour Change (usually called the Stages of Change) was developed by James Prochaska and Carlo DiClemente. It is based on their observations of many types of problem behaviours, including alcohol and other drug use. In this model, change is seen as a gradual, rather than a sudden, event. People don’t just wake up one morning and change their behaviour. The reality is that change happens in stages or cycles. There are five different stages people go through when they change, which are:

- **precontemplation** - the person is not thinking about change;
- **contemplation** - the person is thinking about change in the next little while;
- **preparation** - the person has decided to change and want ideas about how to do it;
- **action** - the person makes a plan and changes their behaviour;
- **maintenance** - the person maintains their new changed behaviour but needs support to maintain it.

In addition to the stages of change, **relapse** can occur. During relapse, the person reverts to their old behaviour. Relapse can happen at any stage and can happen many times.

¹⁶ Prochaska, J. and C. DiClemente (1984). *The Transtheoretical approach: Crossing traditional boundaries of therapy*. Homewood, Ill., Dow Jones-Irwin.

Precontemplation is the stage in which people are not intending to take action in the foreseeable future. In traditional styles of substance abuse counselling, this stage would be called “denial” and a person in precontemplation would be seen as “unmotivated” and not able to be helped. However, in the Stages of Change approach, precontemplators may be in this stage because they are uninformed or under-informed about the consequences of their behavior. Or they may have tried to change a number of times and become demoralized about their ability to change. In either case, precontemplators tend to avoid reading, talking or thinking about their substance use behaviour.

Contemplation is the stage in which people are intending to change in the near future. They are more aware of the benefits (or “pros”) of changing but are also acutely aware of the costs (or “cons”). This balance between the costs and benefits of change can produce profound ambivalence that can keep people stuck in this stage for long periods of time.

Preparation is the stage in which people are intending to take action in the immediate future. They have typically taken some significant action in the past year. These people have a plan of action and are becoming confident in their ability to make their change.

Action is the stage in which people have made specific overt modifications in their substance use or other high risk behaviours within the past six months. The Action stage is also the stage where vigilance against relapse is critical.

Maintenance is the stage in which people are working to prevent relapse. They are less tempted to relapse and increasingly confident that they can continue their change.

Relapse can occur at any stage; indeed, some substance-involved pregnant and parenting women will go through the Stages of Change many times. It is important to speak to women about their lapses and relapses in terms of normal learning experiences. If a woman is demoralized and ashamed of a lapse, she is more likely to go back to precontemplation and stay there for longer. You must remind her that she still has all the learning she acquired before the relapse, that this learning is not wasted, and the lapse provides more information about what to do next time to prevent a relapse.

You can identify which stage of change a substance-involved pregnant and parenting woman is in based on what she says about herself and her substance use. Your first task is to figure out what stage of change the woman is in. The second thing you need to do is to choose an intervention that might move the woman to the next stage of change.

Identifying and Responding Appropriately to a Woman's Stage of Change

Precontemplation

Precontemplation is the first stage of change. Here are some descriptions of people in precontemplation:

- they don't think about change because they are partially or completely unaware that a problem exists, even though others think there is a problem;
- they don't intend to change in the foreseeable future as they are unaware a problem exists;
- they don't think they need to make changes;
- they don't recognize they need help to make changes;
- they are too discouraged to change.

Here are some statements a pregnant woman might make when she is in the precontemplation stage of change:

- *My partner said he'd leave me if I didn't come to see you;*
- *I was told by my Children's Aid worker that if I didn't come see you, I would lose this baby just like I did my first baby;*
- *My family told me that I have a drinking problem. They're a problem, not my drinking. If everyone got off my back, I would be just fine.*

The **service provider's role** in precontemplation is to:

- **develop rapport and establish a relationship;**
- **raise consciousness of risks** involved in substance use without creating guilt or defensiveness;
- **help her move to the contemplation stage of change** - do not rush her to the action stage by providing advice or solutions.

These are the main precontemplation issues for service providers:

- don't try to rush the woman to the action stage of change;
- don't avoid questions about substance use;
- encourage any and all small changes that reduce high-risk behaviours;
- recognize the context of a pregnant woman's life.

Remember: In precontemplation, relationship building - both your relationship with the woman and her relationship with her infant - is your most important job.

Responding to Pregnant Women in the Precontemplation Stage of Change

Here are some **strategies** service providers can use with pregnant women in the precontemplation stage of change:

1. **Raise doubts or concerns** in the woman about her substance use. This is sometimes called *cognitive dissonance*. Use reflection to amplify the woman's concerns. This means you:

- listen for any concerns she expresses
- repeat the concerns back to her in the same or different words

2. **Avoid scare tactics.** Highlight her anxieties without increasing them.

Do say. *Do you have any concerns about your health or your pregnancy?*

Don't use scare tactics. *You will have an FAS baby.*

3. **Create an optimal level of anxiety.** Offer factual information about the risks of substance use during pregnancy. Be objective, sensitive, and honest. Too much anxiety can prevent change. On the other hand, some women might want to be reassured that heavy use is risk-free. Anxiety can motivate pregnant women to change. It's your job to find the right level between too much and too little anxiety.

Do say. *Has any one ever spoken to you about the possible effects of alcohol use during pregnancy?*

This allows you to explore any information she has heard. It allows you to discover the source of the information and its validity. Then, you can clarify and provide her with accurate information.

4. **Explore why other people** say the pregnant woman has a problem. Refer to the areas in her life she believes contribute to her alcohol use.

Do ask. *So when your partner raises concerns about your drinking, what reasons does he give?*

Don't say. *Everyone else sees that you have a problem - why don't you?*

5. **Avoid action statements** about changing her substance use. You are trying to move her to the contemplation stage, not to action. In precontemplation, she does not see herself as having to change her substance use. Your job is to help her change her viewpoint, not change her behaviour. Discuss any other sources of distress, such as threat of apprehension of this child or others, relationship loss, job loss, or legal problems.

6. **Roll with resistance.** Meet resistance with reflection. Never use confrontation. It makes the woman feel defensive.

7. **Use functional analysis.** A functional analysis is a simple motivational strategy. The functional analysis can provide clues or insights about the role of substance use in her life (called its *function*), motivators to change, and barriers to change.

Functional Analysis

A functional analysis is also sometimes called an *ABC* analysis, in which *A* represents *Antecedents*, *B* represents *Behaviour*, and *C* represents *Consequences*. A woman who is using substances is asked to generate the triggers (antecedents) and effects (consequences) of the triggers that might be reasons for her substance use. For people who use substances, their old behaviour that is between the trigger and the effect is substance use. The woman is asked to think of alternative behaviours, besides substance use, that she might engage in to enable her to get the effect she is looking for when certain triggers arise.

The purpose of a functional analysis is:

- to help service providers gain insight into the difficulties substance-involved women confront when they try to change their behaviour and to increase their compassion for the difficult life situations many women live in; and,
- to generate with the woman a range of clear, simple steps she can take that will support change.

Conducting the Functional Analysis

In conducting the functional analysis, have the woman fill in a table listing the triggers for her substance use and the effects derived from it. You may wish to assist her in filling out the first couple of entries to make sure that she understands what you are asking.

Step 1: Here are some questions to ask to prompt her responses:

Tell me about situations in which you have been most likely to drink in the past. Tell me about times when you have tended to drink more. These might be when you were with specific people, in specific places, or at certain times of day, or perhaps when you were feeling a particular way.

When else in the past have you felt like drinking?

What else have you liked about drinking in the past?

Step 2: Have the woman make links between certain triggers and corresponding effects. She can connect the triggers and effect by drawing lines across the columns.

Step 3: Discuss positive ways to get from the triggers to the effects without drinking.

Learning Activity #5: Case Scenario with Functional Analysis

The purpose of this learning activity is to gain experience in completing a functional analysis based on a case scenario.

You will be asked to complete the functional analysis below by generating additional triggers and effects to those provided. You will also be asked to think of alternative behaviours that Lina might engage in to enable her to get the effect she is looking for when certain triggers arise. The facilitator will debrief the exercise in a large group discussion.

Case scenario

Lina has made a few appointments to see you, but today is the first time she actually arrives. She is six months pregnant. She says she sees her physician and is able to identify her pattern of alcohol use. Lina has identified some changes in her consumption during the pregnancy. She was a daily drinker (12 to 18 beers per day) but now doesn't drink as often. She reports 12 to 18 beers four times per week. Lina has some friends who are supportive of sobriety during pregnancy but others who are not. She has been drinking in this way since she was 13 and she has made some treatment attempts, but she cannot imagine her life without alcohol. She has heard from her doctor that alcohol can harm her baby and she's worried about that.

Functional Analysis

<p>Triggers/Antecedents</p> <p><i>When are you most likely to drink?</i></p>	<p>Effects</p> <p><i>What are the effects you want when you drink in these situations?</i></p>
<p>1. When my partner is angry</p>	<p>1. I can say what I think and what's bugging me</p>
<p>2. When my friend Jane comes to visit</p>	<p>2. I like to socialize with Jane</p>
<p>3. When I get the shakes sometimes</p>	<p>3. It helps me calm down</p>
<p>4. When I'm worried about my baby</p>	<p>4. I forget that I'm worried and guilty</p>
<p>5.</p>	<p>5.</p>
<p>6.</p>	<p>6.</p>
<p>7.</p>	<p>7.</p>

Discussion points regarding Learning Activity #5:

Situation 1: What else can Lina do when her partner is angry? (e.g., have a safety plan which she can download from www.shelternet.ca; leave the situation if it is safe for her to do so; or call a friend) Are there other ways she can express herself? (e.g., role-play with a counsellor the issues she needs to discuss with her partner)

Note: It is important to address domestic violence and safety issues for pregnant and parenting women, highlighting for participants that simple advice (e.g., leave him, go to a shelter) may be unrealistic or unsafe for the woman. It is also very unlikely that she would follow through on such advice during pregnancy.

Situation 2: Are there other ways, besides drinking, that Lina can socialize with her friends? What ways can she access the social support she has from friends who understand the importance of abstinence during pregnancy? Are there strategies she can work on to deal with her drinking friends, especially while she's pregnant? (e.g., role-play the responses she could make to friends who entice her to drink)

Note: Just as service providers need a repertoire of responses, women also benefit from a range of clear, simple alternatives to substance use (sometimes called the menu of choice) that they can practice.

Situation 3: Does Lina understand the consequences of heavy consumption of alcohol? (i.e., that “shakes” can be the result of heavy drinking, a physical withdrawal symptom, which dissipate with abstinence)

Note: This situation can be used to illustrate the importance of providing factual, non-judgmental information about the effects of substance use. Service providers must pay close attention to the way they ask questions in this situation (choice of words, tone of voice, body language).

Situation 4: Are there other opportunities for Lina to discuss her fears regarding the health of her infant? What would make it easier for Lina to talk to a service provider about her feelings of shame and guilt?

Note: Participants may recall the core values discussed in Session 1 and discuss the ways they can accord women respect and understanding.

Identifying Pregnant Women in the Contemplation Stage of Change

Contemplation is the second stage of change. Here are some descriptions of people in the contemplation:

- They are ambivalent about change. They see both the negative and positive aspects to their alcohol or other substance use;
- They begin to see positive aspects of change, but are reluctant to give up their alcohol or other substance use completely;
- They simultaneously see reasons to change and reasons not to change;
- They continue to use alcohol but consider the possibility of quitting or cutting back in the near future;
- They might look for information about alcohol or substance use and its effects, re-examine their use, or seek help to support the possibility of change.

Many pregnant women in contemplation will volunteer at least a few hesitant concerns about their substance use, often qualifying concerns with **but**. Here are some statements a pregnant woman might make when she is in the contemplation stage of change:

- *Sometimes I worry about the effect my drinking will have on my baby **but** my sister drank every day and her kids are fine;*
- *I only use on the weekends but sometimes I think about it all week. I want to stop **but** I really enjoy it;*
- *I know I **should** quit, but I'm not sure I **want** to quit. What should I do?*
- *I know I should quit drinking when I'm pregnant **but** it really helps when I feel stressed.*

Your job with women in the contemplation stage is to:

- **help the woman tip the scale** in favour of change;
- **normalize ambivalence.** Reassure the woman that conflicting feelings and uncertainties are common during this stage of change;
- **help her move to the preparation stage of change.** Again, it is very important to resist the urge to push the woman to the action stage.

In summary, these are the main contemplation issues for service providers:

- avoid blame;
- normalize ambivalence;
- avoid commands - don't let statements sound like accusations;
- show curiosity and interest;
- avoid focus on the use of substances per se - illuminate the relationship between use and the reasons for use;
- increase self-efficacy: remember from session 3 that high self efficacy is a predictor of successful change;
- recognize that ambivalence has consequences for you, too.

Responding to Pregnant Women in the Contemplation Stage of Change

1. **Reassure her** that her confused feelings are typical.

Do say. *Many pregnant women I know were confused in the contemplation stage but eventually they changed their substance use.*

Don't say. *You've given me a lot of your reasons to quit - now all you have to do is stop drinking.*

2. **Tip the scale.** There are several strategies you can use here. The goal is to tip the balance in favour of the positive aspects of change.

Strategy #1: Reflect both sides of her ambivalence, but place greater stress on the perceived problems.

Do say. *So on the one hand, you don't think you have a problem with alcohol, but on the other hand, your drinking is starting to scare you and you worry about yourself and your baby.*

Don't say. *You've got a serious problem with alcohol if you're that worried about all the effects it can have.*

Strategy #2: Examine all her reasons for change.

Help her identify her own reasons for change, rather than reasons others give her. Encourage discussion. Find a natural link between external motivators and internal ones she is unaware of or finds difficult to express; for example:

Do make this link. *CAS is threatening to take your baby because they're concerned your alcohol use will lessen your ability to be a good parent. You've talked a lot to me about how important it is to you to be a good parent. What changes do you think you need to make so you can be a better parent?*

Don't say. *CAS will take your baby because you can't be a good parent when you drink. So your choice is clear - quit drinking or lose your baby.*

Other strategies that help you change extrinsic to intrinsic motivation are to:

- show curiosity about the woman;
- show interest and maintain it over time;
- take a holistic approach and discuss all her issue areas, not only substance use;
- reframe negative external motivators and give them a positive meaning, such as:

Do say. *So it feels like your husband is always nagging you about your drinking. Your marriage must be important to you since you came to see me today.*

Don't say. *So your husband thinks you should quit drinking. Why don't you agree with him?*

Strategy #3: Use a decisional balance index (see page 37 for a description of a Decisional Balance Index)

4. **Recognize that ambivalence has consequences for you, too.** Remember: ambivalence is the primary characteristic of the woman in contemplation. Here are some traps service providers should try to recognize and avoid:

- **you underestimate her ambivalence.** You push the woman too hard, too fast, which leads to resistance.
- **you over-prescribe.** You give too much advice which leaves the woman overwhelmed or takes away her personal choice and control.
- **you don't give enough direction.** You don't give feedback or advice when she asks for it.

Remember: Don't move ahead too quickly - resist the temptation to be action-stage focused. Your task is to move the woman, gently and persuasively, to the preparation stage of change.

Decisional Balance Index (DBI)

Janis and Mann¹⁷ conceptualized decision-making as a decisional *balance sheet* of comparative potential benefits and costs. The pros and cons combine to form a decisional *balance sheet* of comparative potential benefits and costs.

When completing a pros and cons chart (also called a *Decisional Balance Index*) with a woman, ask the woman to list the benefits of, and the drawbacks to, change. Also ask her to list the benefits of, and the drawbacks to, substance use. This is a good strategy for both the woman and the service provider. It's a concrete visual aid to help the woman make decisions. And it helps the service provider see the negative and positive reasons for her alcohol use.

Decisional Balance Index (DBI) Template

Changing My Substance Use	Continuing to Use Substances
<i>Benefits of change</i>	<i>Benefits of continued use</i>
<i>Costs of change</i>	<i>Costs of continued use</i>

¹⁷ Janis, I. L., & Mann, L. (1977). *Decision making: A psychological analysis of conflict, choice, and commitment*. London: Cassel & Collier Macmillan.

Learning Activity #6: Case Study with Decisional Balance Index (DBI)

The purpose of this learning activity is to help you understand how to complete a Decisional Balance Index.

1. Review Maria's story and then generate at least **five** distinct points in **each** quadrant of the DBI. Use the blank DBI provided on the next page;
2. The facilitator will discuss the results with the group, asking you to focus on the **positive** role substance use plays in Maria's life and the **drawbacks** of quitting use;
3. You will be asked, as a group, to generate a **menu of options** as "small step" replacements for substance use in Maria's life.

Maria's story

I left home when I was 16 because I was being sexually abused by my father, who was the doctor in our small community. I moved to Toronto and started working on the streets. My family disowned me and I haven't spoken to them since. Within about a year, I had started using cocaine quite regularly. I moved in with my boyfriend and pretty soon I was pregnant. Because I was using cocaine, it suppressed my appetite, so I actually was losing weight while I was pregnant. I went to a few prenatal classes at the Community Health Centre - they gave me milk coupons there but my boyfriend always took them and sold them to other people so he could buy drugs. Just before my baby was born, my boyfriend left me. When I had the baby, he was screened for drugs. Because he tested positive, the hospital called Children's Aid. I couldn't seem to stop using drugs, so after a while, the baby was taken into foster care.

I realised I needed to get my life together. I moved to a smaller town to get away from the street life in Toronto. I quit using cocaine, but I guess I drink too much. I got a job as a waitress - the pay wasn't great but the tips were OK and it meant that I didn't have to apply for welfare. I found a little apartment and a new boyfriend, who moved in with me. He works when he can find construction jobs but usually they want people who are more skilled than he is and there is never much work for him in the winter, anyway. He uses a lot of drugs when he's not working. He can sometimes get pretty mean with me, too.

Now, I'm pregnant again. I can't work as much, because I can't be on my feet as long. So we have a lot less money than we usually have. There's never much food in the house. When I found out I was pregnant, I tried to cut back on my drinking but it's really hard. I'm worried CAS is going to take this baby, too.

Maria's DBI

Changing My Substance Use	Continuing to Use Substances
<p style="text-align: center;"><i>Benefits of change</i></p> <p>1.</p> <p>2.</p> <p>3.</p> <p>4.</p> <p>5.</p>	<p style="text-align: center;"><i>Benefits of continued use</i></p> <p>1.</p> <p>2.</p> <p>3.</p> <p>4.</p> <p>5.</p>
<p style="text-align: center;"><i>Costs of change</i></p> <p>1.</p> <p>2.</p> <p>3.</p> <p>4.</p> <p>5.</p>	<p style="text-align: center;"><i>Costs of continued use</i></p> <p>1.</p> <p>2.</p> <p>3.</p> <p>4.</p> <p>5.</p>

Example of a completed DBI

Changing My Substance Use	Continuing to Use Substances
<p style="text-align: center;"><i>Benefits of change</i></p> <ol style="list-style-type: none"> 1. It's better for my baby 2. It's better for my relationship with Tom 3. I'll save money 4. I won't have to worry about CAS 5. I'll have more energy 	<p style="text-align: center;"><i>Benefits of continued use</i></p> <ol style="list-style-type: none"> 1. Drinking curbs my appetite 2. It helps me forget about my father 3. I like to socialize with Tom 4. All my friends drink and I like to go out to the bar with them 5. Drinking helps me relax
<p style="text-align: center;"><i>Costs of change</i></p> <ol style="list-style-type: none"> 1. When I get anxious and depressed, I won't know how to feel better 2. When I have a fight with Tom, I might get really angry and do something stupid 3. I won't be able to go out with my friends anymore 4. I'll have trouble sleeping 5. I feel better about myself when I've had a few drinks 	<p style="text-align: center;"><i>Costs of continued use</i></p> <ol style="list-style-type: none"> 1. CAS will probably take my baby 2. I might start drinking way too much and go back to using cocaine 3. Tom and I will have a lot of fights 4. I might end up back on the street 5. It's bad for my health

Identifying Pregnant Women in the Preparation Stage of Change

Preparation is the third stage of change. Here are some descriptions of people in preparation:

- They show decreased resistance;
- They have fewer questions about the problem and more questions about how to change;
- They have reached a resolution and are more peaceful, calm, relaxed or settled – but this might occur only after a period of anguish or discomfort;
- They express self-motivational statements that show optimism and an openness to change;
- They envision life after change occurs and anticipate difficulties and advantages of change;
- They experiment with possible change approaches.

Here are some statements a pregnant woman might make when she is in the *preparation* stage of change:

- *I've really thought about it and I know I have to do something about my drinking problem. I just don't know where to begin;*
- *I've decided to stop drinking because of my baby;*
- *I have to stop smoking but it's going to be really hard;*
- *Now that I know I'm pregnant, I want to quit drinking. I hope my partner can quit, too.*

The **service provider's role** in *preparation* is to:

- **negotiate a change plan** that reflects the woman's values and goals. Clarify her goals and strategies for change and emphasize her personal choice and responsibility for change. Develop a contract;
- **offer a menu of choice** – provide as many options for change as possible and allow her to select those options she perceives to be the most helpful;
- **reduce barriers to change** – provide childcare, transportation, telephone support, and enlist social support;
- **focus on self-efficacy** and reinforce any self-motivational statements;
- **reflect the contradictions** between the woman's goals for the future and her current behaviour. Help her to recognize the conflict between where she is now and where she hopes to be;
- **continue to evaluate readiness to change**. Be prepared for ambivalence or resistance.

Remember: Change is rarely linear. Ambivalence can occur at any stage of change. It may be necessary to return to the contemplation stage of change until the woman is ready to move to action.

Identifying Pregnant Women in the Action Stage of Change

Action is the fourth stage of change. Here are some descriptions of people in the action stage:

- they take steps to change but have not yet reached a stable state
- they actively modify their habits and environment to support their change plans
- they make drastic lifestyle changes
- they face challenging situations and emotions that can surface after they change their alcohol use
- they reevaluate their self-image, from a problem user to a safe user or non-user

Some statements a pregnant woman might make in the *action* stage are:

- *This is really hard. I wasn't hung over the other day and that was new.*
- *Sometimes I wonder if I can keep this up it's so weird.*
- *My family isn't being supportive. I guess they've seen this all before.*
- *I have to do something about my partner who hits me. I can't take it now that I'm sober.*

The service provider's role in *action* is to:

- **help her act on the achievable goals** set out in the change plan
- **provide positive feedback** for any change she makes
- **refrain from negative comments or actions** if she has a relapse
- **acknowledge and find support for** underlying issues that surface during this stage
- **help her move** into the maintenance stage of change

Action issues for service providers:

- address unrealistic hopes and fears
- reduce or eliminate barriers to change where possible
- help the woman grieve the loss of alcohol in her life
- help her enlist family and social support

Remember: Relapse is a natural part of the stages of change. It doesn't mean the woman has failed. Relapse is a learning experience. Use it to find better ways to change.

Identifying Pregnant Women in the Maintenance Stage of Change

Maintenance is the fifth stage of change. Here are some descriptions of people in maintenance:

- they work to sustain the changes they have made
- they build a new lifestyle to support the changes they have made
- they learn to identify and plan strategies to deal with triggers that lead to alcohol use
- they identify risky situations and practise new coping strategies to deal with them
- they find new sources of support for their new lifestyle
- they look back over the past which can bring up painful issues and lead to feelings of guilt and remorse

Some statements a pregnant woman might make in the *maintenance* stage are:

- *I feel so guilty that I've been able to stop drinking for this baby, but I didn't for my other kids.*
- *My son is having problems at school. I went to see his teacher and she said he's really angry with me. He told her that, when I was drinking, I was never around but now that I'm sober, I want to set all kinds of rules. I was really hurt. I feel terrible about what's happened.*
- *I was thinking about when I used to drink and how that must have been really hard for my family.*
- *I really feel better these last few months since I've quit drinking. But I'm still wondering if abstinence is really necessary.*

The primary goals for the service provider in the *maintenance* stage are to:

- **assist in relapse prevention**, and identify alternatives to alcohol or other drug use
- **provide support around other issues** that arise, either directly or by referral. Make referrals and other linkages as easy as possible for her
- **support lifestyle changes**
- **affirm her resolve and self-efficacy**, and continue to use motivational strategies
- **maintain supportive contact**

Remember: After a relapse, people usually return to an earlier stage of change, often to some level of contemplation. So, return to the strategies you used in precontemplation and contemplation.

Conclusion

There are defined strategies or tasks a service provider can take on with substance-involved pregnant and parenting women for each stage (particularly precontemplation). In the early stages of change, it is extremely important for service providers to avoid action stage responses. In precontemplation and contemplation, the risk is that action stage responses will create a backlash in the woman and she will remain *stuck* in the early stages for much longer than necessary. The goals for service providers in precontemplation and contemplation are to build a relationship with the woman and raise cognitive dissonance in a way that will tip the scale in favour of change. Gently raise doubts and concerns to lead the woman eventually to action.

Learning Activity #7: Stages of Change and the Service Provider's Task***The Learning Activity***

The purpose of this learning activity is to help you identify the stage of change that a woman is in by analysing what she says. This will allow you to apply motivational counselling strategies appropriate to the woman's stage of change. Complete the worksheet that follows by:

1. Identifying the stage of change reflected by various statements made by substance-involved pregnant and parenting women;
2. For each statement, generating two or three statements you could make in response to the woman that would show you are in tune with her stage of change and are attempting to meet her at that stage.

Answer the questions on the Worksheet that follows:

Stages of Change and the Service Provider's Task

Instructions

Identify the stage of change reflected by the following statements made by substance-involved pregnant and parenting women.

For each statement generate two or three statements you could make in response to the woman that would show that you are in tune with her stage of change and are attempting to meet her at that stage.

1. *My partner said he'd leave me if I didn't come to see you.*
a) precontemplation; b) contemplation; c) preparation; d) action; e) maintenance

Possible Responses:

2. *I only use on the weekends but sometimes I think about it all week. I want to stop **but** I really enjoy it.*
a) precontemplation; b) contemplation; c) preparation; d) action; e) maintenance

Possible Responses:

3. *I know I **should** quit, but I'm not sure I **want** to quit. What should I do?*
a) precontemplation; b) contemplation; c) preparation; d) action; e) maintenance

Possible Responses:

4. *My family told me that I have a drinking problem. They're a problem, not my drinking. If everyone got off my back, I would be just fine.*
a) precontemplation; b) contemplation; c) preparation; d) action; e) maintenance

Possible Responses:

5. *Now that I know I'm pregnant, I want to quit drinking. I hope my partner can quit, too.*
a) precontemplation; b) contemplation; c) preparation; d) action; e) maintenance

Possible Responses:

6. *My family isn't being supportive. I guess they've seen this all before.*
a) precontemplation; b) contemplation; c) preparation; d) action; e) maintenance

Possible Responses:

7. *I was thinking about when I used to drink and how that must have been really hard for my family.*
a) precontemplation; b) contemplation; c) preparation; d) action; e) maintenance

Possible Responses:

8. *I think I might be pregnant, I haven't had a period in a few months. My social worker says I should quit drinking just in case, but I only have a couple of beers on the weekends.*
a) precontemplation; b) contemplation; c) preparation; d) action; e) maintenance

Possible Responses:

9. *Sometimes I worry about the effect my drinking will have on my baby **but** my sister drank every day and her kids are fine.*
a) precontemplation; b) contemplation; c) preparation; d) action; e) maintenance

Possible Responses:

SESSION 5:

IDENTIFICATION OF CHILDREN
AFFECTED BY FASD

Session 5: Identification of Children Affected by FASD

Objectives/Outcomes

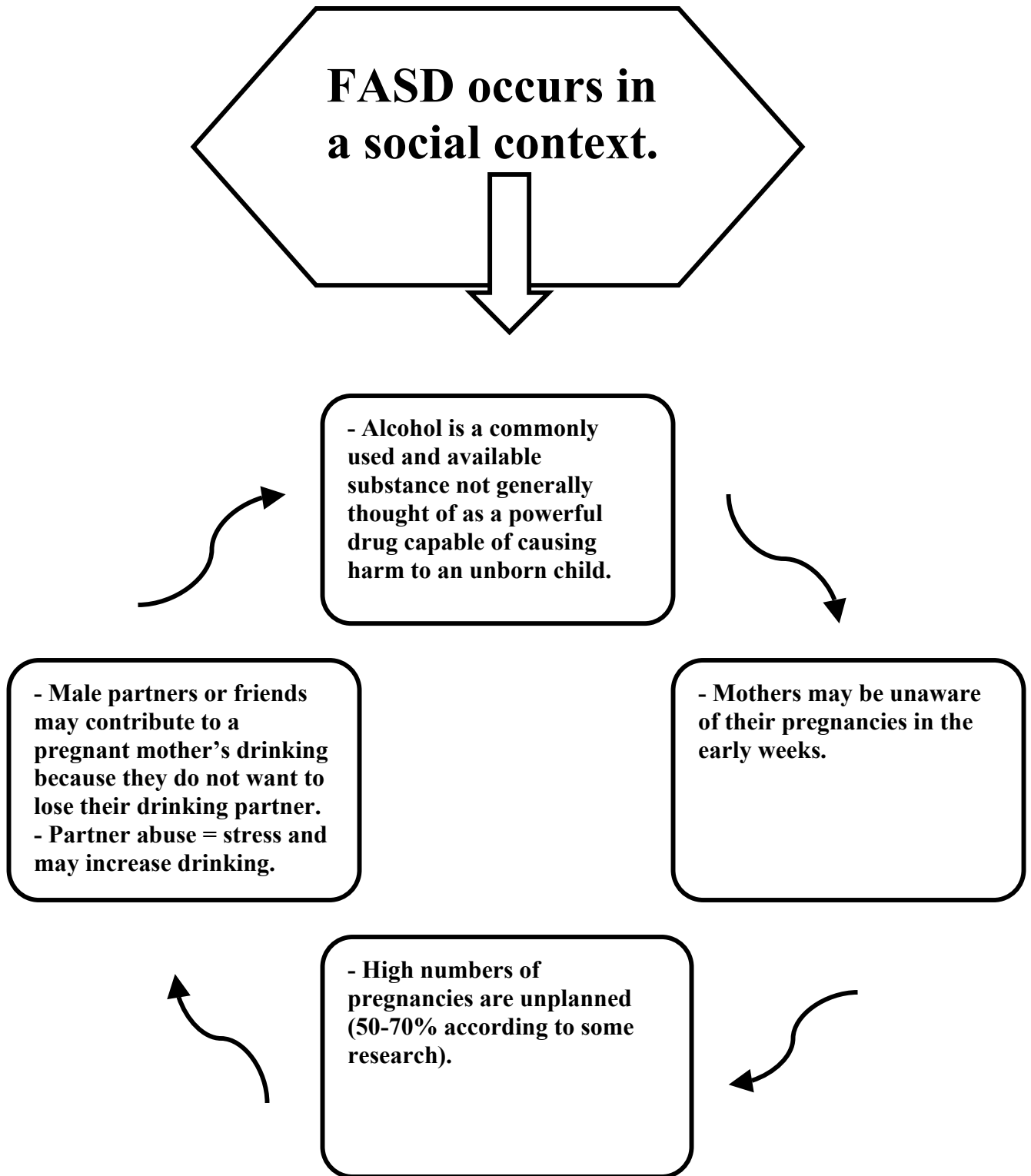
By the end of this session you will:

- become familiar with process of assessment and the diagnostic categories along the FASD continuum;
- enhance your capacity to identify children who may be affected by prenatal alcohol exposure;
- increase your skills in supporting families to explore diagnosis and to adjust to the outcome of the diagnosis.

Key questions

1. Am I able to identify children and support families who are affected by FASD?
2. Am I able to assist families to investigate a diagnosis for their child?
3. Am I able to support families in understanding, accepting and adjusting to the assessment outcome?

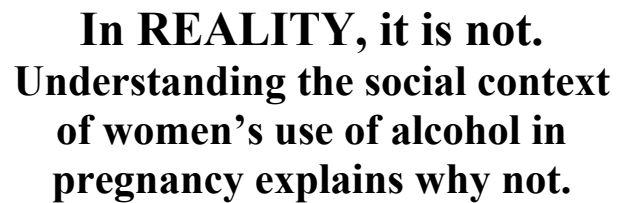
Social Context of FASD



FASD is Preventable in Theory Only



**FASD is preventable 100%
of the time in THEORY
ONLY.**



**In REALITY, it is not.
Understanding the social context
of women's use of alcohol in
pregnancy explains why not.**

Learning Activity # 8: Understanding Feelings

The purpose of this activity is to identify and understand the range of feelings and emotions experienced by those affected by prenatal alcohol exposure. Understanding the feelings of the child affected by prenatal alcohol exposure, of their families and caregivers, and of service providers who support them, is a critical first step towards understanding the importance of identification and the introduction of appropriate support.

Remember the guiding principles that are applied when identifying and supporting children affected by prenatal alcohol use and their families:

- Respect
- Understanding
- Compassion
- Hope
- Responsibility

The Learning Activity

1. The large group is divided into three small groups.
2. Each group represents one of the following:
 - a) a **family** raising a child who has been affected by prenatal alcohol exposure
 - b) a **child** who is affected by prenatal alcohol exposure
 - c) a **service provider** supporting a family
3. Based on the group that they are in, participants are instructed to write a word on a piece of paper that describes a feeling that a family member, a person or a service provider might feel in raising a child with FASD. They may write as many feeling words as possible using a separate piece of paper for each, and placing each into a bowl or a bag.
4. The container is then passed to each member of the group. Each person draws 2-3 pieces of paper. As each piece of paper is drawn, the participant states the feeling word and the facilitator writes the word on the flip chart (one flip chart each for a, b, and c responses)
5. When all the words have been noted, the facilitator will lead a group discussion about what might lead the family, person or service provider to have these particular feelings, and how these feelings might change with identification and support.

The FASD Continuum¹⁸

A woman's use of alcohol during pregnancy affects the developing fetus, causing a range of physical and neurological defects. The impact of alcohol varies with the amount, timing and frequency of alcohol consumed, and depends on a number of other factors, including the genetics of the fetus and woman, the health status of the woman, and other social, economic, physical and environmental factors.

In pregnancy, alcohol crosses the placenta at the full concentration that is ingested by the woman, and enters the circulatory system of the fetus. Because of the baby's small size and underdeveloped liver and enzyme system, it cannot eliminate the alcohol at the same rate as the mother can, so the fetus is exposed to alcohol for longer periods than the drinking mother. Alcohol is a toxic agent that can damage cells in the developing organs. Damage to the cells causes malformation to growing organs, and all fetal organs can be adversely affected. The fetus is forced to divert its energy to metabolize the alcohol instead of using energy to grow healthy cells and tissues. While the alcohol is in the unborn baby's system, it causes damage. The damage caused by fetal alcohol exposure is permanent. Because fetal brain development occurs throughout pregnancy, drinking at any time during pregnancy can damage the brain. Alcohol affects neural organization in the cortex, and impairs the ability for reasoning and problem solving later in life.

In Canada the incidence of Fetal Alcohol Spectrum Disorder (FASD) has been estimated to be 1 to 9 per 1000 live births. FASD is the leading cause of developmental and cognitive disabilities among Canadian children.¹⁹

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that reflects the fact that prenatal alcohol exposure may result in a range of effects along a continuum, with differing degrees of expression of dysfunction and malformation. Five diagnostic categories appear along the FASD continuum, and are described below.

Assessment and Diagnosis

Fetal Alcohol Syndrome (FAS) was first reported by Lemoine et.al. (1968)²⁰ and then independently identified and named by Jones and Smith (1973)²¹. In 1996, the Institute of Medicine²², proposed a revision of the diagnostic criteria for FAS and other alcohol-related effects to reflect current knowledge of the field.

¹⁸ Sessions 5-8 of the manual will concern themselves exclusively with alcohol use in pregnancy and FASD.

¹⁹ Health Canada (2003). *Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action*. Ottawa: Minister of Public Works and Government Services Canada.

²⁰ Lemoine, P. et.al. (1968). *Les enfants de parents alcoolique: Anomalies observees a propos de 127 cas. [The children of alcohol parents: Anomalies observed in 127 cases]*. *Quest Medicale*, 2:476-482

²¹ Jones, K.L. & Smith, D.W. (1973). *Recognition of the Fetal Alcohol Syndrome in early infancy*. *The Lancet*, November:999-1001.

²² Stratton, K., Howe, C., & Battaglia, F. eds. (1996). *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment*. Washington, D.C.: National Academy Press.

The following are two key revisions in the diagnostic classifications developed in 1996:

- **Establishment of a category for assigning the FAS diagnosis without maternal history**, when all other necessary conditions are present. For children in the foster care system, foreign adopted children, and for fostered or adopted adults, information regarding prenatal exposure is often uncertain or unavailable. In other cases, the birth mother may not recall the specifics of her alcohol use in pregnancy or may be unwilling to report her use accurately. This category allows for the possibility of the diagnosis -- and the clinical benefits that come with the diagnosis -- when all other necessary conditions are present.²³
- **Elimination of the term Fetal Alcohol Effect (FAE)**, which had been criticized for lacking specificity and sensitivity. Because of this, it was difficult to identify appropriate services or plan appropriate interventions.

Remember: Identification of FASD is greatly facilitated by an accurate history of the mother's alcohol use in pregnancy, which is best gained within the context of a trusting, respectful and non-judgmental relationship with the mother.

Diagnosis of FASD requires a multidisciplinary focus. Diagnostic teams often include:

- **Physician(s)**: family physicians, pediatrician, developmental pediatrician and/or a geneticist to determine growth and developmental patterns of the child; to define characteristic facial features; to rule out other genetic disorders often confused with FASD; to complete vision and hearing assessments;
- **Psychologist** to assess the behaviours that would support the finding of central nervous system anomalies, such as mental retardation, learning disabilities or adjustment problems;
- **Occupational therapist and/or physiotherapist** to assess problems with sensory processing, regulatory function, gross and fine motor skills and coordination;
- **Speech and language pathologist** to assess communication skills;
- **Social worker** to provide support, counseling and case management support to families.

Remember: Many symptoms of prenatal exposure to alcohol are also symptoms of other birth defects and illnesses. Only qualified diagnosticians using a multidisciplinary approach can accurately make this complex assessment and diagnosis. Incorrect diagnosis results in inappropriately labelling and stereotyping of children, prevents the establishment of appropriate interventions and supports, and causes unnecessary grief for children and families.

²³ Despite the opportunity to do so under these diagnostic classifications, most diagnosticians remain reluctant to give a diagnosis of FAS without a confirmed history of maternal alcohol use in pregnancy.

Diagnostic Categories

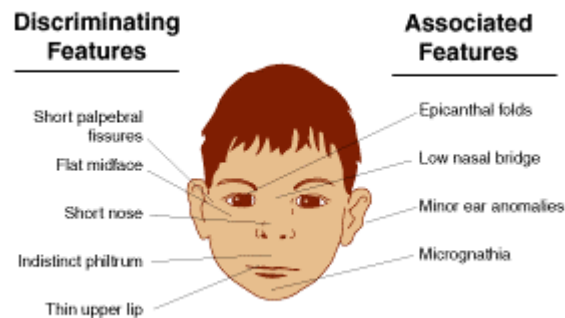
Here are the five diagnostic categories for FASD:²⁴

Category 1: Fetal Alcohol Syndrome with confirmed maternal alcohol exposure

1. Prenatal and/or postnatal growth restriction:
 - Low birth weight;
 - Decelerating weight over time, not due to malnutrition;
 - Disproportional low weight to height;
 - Height and weight below the 10th percentile.

2. Central nervous system involvement:
 - Neurological abnormalities (incl. impaired motor skills, poor coordination, hearing loss, visual problems);
 - Decreased head size (microcephaly);
 - Behavioural dysfunction (incl. problems in memory, attention, reasoning and judgement, mental handicap, learning difficulties, deficits in some mathematical and language skills);
 - Structural abnormalities of the brain.

3. Characteristic facial features:
 - Small eye openings (palpebral fissures);
 - Thin upper lip;
 - Flattened cheekbones;
 - Flattened groove between nose and upper lip (philtrum).



Category 2: Fetal Alcohol Syndrome without confirmed maternal alcohol exposure

If the triad of signs described in category 1 is present, a diagnosis of FAS may be made even in the absence of confirmed maternal alcohol exposure.

²⁴ Stratton, K., Howe, C., & Battaglia, F. eds. (1996). Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment. Washington, D.C.: National Academy Press.

Category 3: Partial FAS (pFAS)

1. Evidence of some components of the pattern of characteristic facial anomalies;
2. Evidence of one other component of FAS, I.e. growth deficiency or neurological involvement, including related behavioural and cognitive problems;
3. Confirmed history of maternal alcohol use in pregnancy.

Category 4: Alcohol Related Birth Defect (ARBD)

1. Congenital anomalies, including:
 - Skeletal abnormalities;
 - Heart defects;
 - Cleft palate and other craniofacial abnormalities;
 - Kidney and other internal organ problems;
 - Vision and hearing problems.
2. Confirmed history of maternal alcohol use in pregnancy.

Category 5: Alcohol Related Neurodevelopmental Disorder (ARND)

1. Central nervous system abnormalities, including:
 - Microcephaly;
 - Structural brain abnormalities;
 - Neurological hard or soft signs (e.g. impaired fine motor skills, hearing loss, poor gait, poor eye-hand coordination);

and/or

2. Behavioural or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as:
 - Learning difficulties;
 - Poor impulse control;
 - Problems in social perceptions;
 - Poor capacity for abstraction;
 - Problems in memory, attention and judgment;

Remember: Diagnoses along the FASD continuum must be given by a physician.

Identifying Children with FASD

The Importance of Identification

FAS is often called the “hidden disability”. Because the primary damage of prenatal alcohol exposure is to the brain, the affected child usually does not have a visible handicap that signals the need for special services or adaptations. The signs of brain damage due to prenatal alcohol exposure include learning/behavioural problems, social/communication problems, sensory and regulatory sensitivities. Identification of children with FAS or other alcohol-related effects provides benefits to the mother, the child and to society.

- The process of engaging the mother in the identification and assessment of a child with prenatal alcohol exposure may assist her in resolving feelings of guilt and self-blame regarding the effects of her alcohol use in pregnancy. Most mothers are eager to do all they can to assist their child in accessing the interventions and supports that they may require. The process may also motivate her to address her substance use issues, and prevent the births of subsequent who may be affected.
- Children with FASD have neurological impairments that cannot be reversed, but may be improved with appropriate interventions; conversely, they can be made worse when ignored or misunderstood. Generally, diagnosis of FASD helps parents, caregivers, educators and others to understand that the child *can't* perform as opposed to *won't* perform. This change in awareness can prevent misinterpretations of the child's behaviour and avoid inappropriate discipline and punishment. The diagnosis can lead to treatment plans that centre around and support the child and prevent the development of secondary disabilities.
- The primary disabilities of FASD are those that reflect the neurological damage that is sustained in utero. Secondary disabilities are those that an individual is not born with, and that could presumably be ameliorated through better understanding and appropriate interventions. The prevention of secondary disabilities benefits children, their parents and families, and society as a whole.

Remember: “Identification is pivotal. It is hard to think of a more radical perceptual shift than the one between ‘willful misconduct’ to ‘organicity’; from ‘bad child’ to ‘*a child with neurological differences*’ who has potential”²⁵

²⁵ Kleinfeld, J. & Wescott, S. Eds. (1993). *Fantastic Antone Succeeds: Experiences in Educating Children with Fetal Alcohol Syndrome*. University of Alaska Press.

Secondary disabilities study²⁶

Ann Streissguth and her colleagues used a Life History Interview (LHI) to examine secondary disabilities in 473 individuals diagnosed with FAS (n=178) and FAE (n=295). Six main secondary disabilities were identified:

1. **Mental Health Problems** were experienced by over 90% of the full sample.
2. **Disrupted School Experience** (defined as having been suspended or expelled from school or having dropped out of school) was experienced by 60% of the sample (12 and over).
3. **Trouble With the Law** (defined as ever having been in trouble with authorities, charged or convicted of a crime) was experienced by 60% of the clients (12 and over).
4. **Confinement** (including inpatient treatment for mental health problems or alcohol/drug problems, or ever having been incarcerated for a crime) was experienced by about 50% of the clients.
5. **Inappropriate Sexual Behaviour** was noted for about 50% of the clients (12 and over).
6. **Alcohol/Drug Problems** were noted for about 30% of the clients (12 and over).

To determine levels of independence in adulthood, two additional categories were identified for individuals 21 years of age and older (median age 26):

7. **Dependent Living** characterized about 80% of the sample
8. **Problems with Employment** characterized about 80% of the sample

The study identified a set of **protective factors for secondary disabilities**. Eight factors emerged that are almost universally protective in terms of secondary disabilities. In order of their strength as “universal” protective factors, they are:

1. Living in a stable and nurturant home for over 72% of life;
2. Being diagnosed before the age of 6 years;
3. Never having experienced violence against oneself;
4. Staying in each living situation for an average of more than 2.8 years;
5. Experiencing a good quality home from age 8 – 12 years;
6. Having applied and been found eligible for developmental disability services;
7. Having a diagnosis of FAS rather than FAE;
8. Having basic needs met for at least 13% of life.

²⁶ Streissguth, A.P., et.al. (1996). *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)*. Seattle: University of Washington School of Medicine.

Indicators of prenatal alcohol exposure and/or possible FASD:

Sensory sensitivity:

- The child may become over-stimulated when around groups of other people, or by sensory stimuli such as bright lights, loud noises, seams on clothing, being touched, certain smells, and so on;
- The child may have a high or low tolerance to pain;
- The child may have strong food preferences for certain tastes (spicy or bland) or certain textures (crunchy or smooth);

Problems with regulation:

- The child may suffer sleep disturbances including difficulty falling asleep, staying asleep, or sleeping for a much shorter or longer time period than other children;
- The child may exhibit difficulties with eating. S/he may eat much more than other children yet not gain weight. Alternatively, s/he may appear to eat too little or forget to eat;
- The child may overreact strongly to certain situations, such as transitions or changes in routine, because they have difficulty shifting activities (perseveration);

Learning/behavioural problems:

- The child may have a poor attention span, difficult completing tasks, or frequently lose things;
- The child may have a developmental delay;
- The child may be unaware of the consequences of his/her behaviour, and therefore engage in risky behaviour, or be unable to learn from consequences;
- The child knows the rules, can repeat the rules, but is unable to comply with the rules;
- The child forgets what s/he is doing part way through a task, or exhibits other problems with memory;
- The child may have difficulty sequencing and predicting;
- The child may have difficulty learning from auditory information because of a slower rate of processing;
- The child may engage in strange or puzzling behaviours;
- The child may have difficulty with abstract concepts.

Social/Communication problems:

- The child may be indiscriminate with strangers, including hugging strangers, or willing to go with strangers;
- The child may not be able to pick up on social cues;
- The child does not pick up on subtle hints from caregivers, and needs to be told clearly and concretely exactly what to do, over and over again;
- The child may get 'stuck' on certain words or behaviours (perseveration);
- The child may act younger than his/her chronological age;
- The child may tell 'tall stories' or be perceived to 'lie' a lot (confabulation).

SESSION 6:

SUPPORTING FAMILIES AFFECTED BY
FASD

Session 6: Supporting Families Affected by FASD

Objectives/Outcomes

By the end of this session you will:

- understand how to apply the Stages of Change framework to identify the readiness of parents and caregivers to consider prenatal alcohol exposure as a reason for their child's difficulties
- enhance your skills in talking with parents and families about FASD
- enhance your awareness of the types of supports that may be required for families dealing with FASD.

Key questions

This session will provide you with answers to the following questions:

1. How can I use the Stages of Change framework to identify the readiness of parents and caregivers to consider FASD?
2. What is my role in supporting parents and caregivers at each different stage of change using motivational interviewing strategies.
3. What supports are required by families dealing with FASD?

Supporting Families Affected by FASD

Children with FASD may be cared for by biological parents, foster or adoptive parents, or extended family members. Other caregivers with whom they may develop relationships in their early years include childcare providers, health care personnel, social workers and teachers. They are all important in touching the life of a child with FASD.

Early identification and intervention are important so that parents and caregivers can accurately understand that their child's challenges or "differences" are not due to wilful misbehaviour, but a result of neurological impairment. When parents and caregivers understand the reason for the difficulties, and the child understands that it is not his or her fault, they have taken an important first step in developing a life plan that can accommodate and circumvent problems, prevent secondary disabilities and prevent another generation of individuals affected by FASD.

As parents and caregivers come to recognize their child's differences, acknowledge and accept the reason for the differences, and embark on the process of accessing appropriate assessment, diagnostic, and intervention services, they require different types of support. The process of recognition, acknowledgement, acceptance and action is a gradual, rather than a sudden, event. While all parents may experience similar feelings during this process – e.g. guilt, shame, depression, anger, grief and mourning – the source of these feelings may vary depending on whether it is a biological parent, foster or adoptive parent, or an extended family member. It is important to be sensitive to their experiences and responses.

Stages of Change Model (See Session #4)

The Stages of Change Model is an effective framework for determining the readiness of parents and caregivers to consider the role of prenatal alcohol exposure in their child's difficulties, and for guiding service providers' responses and interventions. Just as is the case for working with pregnant women, families of children who may be affected by prenatal alcohol exposure require support and interventions that match their needs and that acknowledge their stage of readiness to change – or to shift their paradigm for understanding their child's "differences".

Remember the five stages of change:

1. Precontemplation
2. Contemplation
3. Preparation
4. Action
5. Maintenance

You can identify which stage of change a parent or caregiver is in based on what they say about their child. Your first task is to figure out what stage of change the parent or caregiver is in. The second thing you need to do is to choose an intervention that might move them along the process towards the next stage of change.

Precontemplation

This is the stage in which parents or caregivers are not intending to consider the role of prenatal alcohol exposure as a source of their child's difficulties or to change their approaches.

Here are some statements that parents or caregivers might make in the precontemplation stage:

- *“There is nothing wrong with this child. The teacher just doesn't know how to handle him”;*
- *“Children with FASD are just like any other child in this classroom. We don't need to do anything differently.”*

The **service providers' role** in precontemplation is to:

- **develop rapport and establish a relationship with the parents or caregivers** by listening empathically and non-judgementally
- **raise consciousness of the possibility that prenatal alcohol use** may be a factor in the child's difficulties by:
 - raising doubts or concerns;
 - avoiding scare tactics;
 - exploring why other people are considering the possibility of prenatal alcohol exposure;
 - providing information about effects of prenatal alcohol exposure;
 - avoiding action statements. In precontemplation, your goal is to change the parents' or caregiver's viewpoint, not their behaviour.

Remember to use motivational interviewing strategies:

Be non-judgemental. Make sure you have resolved any issues, strong opinions, or judgments you have about alcohol use in pregnancy;

Be empathic. Recognize that birth mothers are often just as hurt and victimized as the child who was prenatally exposed to alcohol. Parents may feel guilty about how they have parented;

Be respectful. Not every birth mother is ready to discuss her substance use during pregnancy. She may experience shame, guilt or grief when she realizes that her prenatal alcohol use may have caused her child to have difficulties;

Be gentle. Any discussions with a birth mother should be very tentative, giving her lots of room to save face, while leaving the door open to later discussions. She may not be ready to accept that her child has a life-long disability;

Roll with resistance. Ideally, you should have a positive relationship with the woman. This will help your skill in reading the woman's reactions and help you know when to back off if she becomes uncomfortable;

Be knowledgeable. In particular, it is important to understand the social context that surrounds a woman who uses substances during pregnancy;

Be receptive. Parents have valuable experience in parenting their child.

Contemplation

This is the stage in which parents or caregivers begin to consider a paradigm shift in the way they view their child and what their child needs. Here are some descriptions of parents or caregivers in contemplation:

- They are **looking for information** about the effects of prenatal alcohol exposure on children and are thinking about the child's prenatal history;
- They are **ambivalent** about acknowledging that their child's difficulties may be due to prenatal alcohol exposure. They begin to recognize that their child may be affected by prenatal alcohol exposure, but are reluctant to fully commit to following up on this possibility;
- They **begin to realize** that the child needs something different, **but** they feel overwhelmed by the requirements to adjust the environment and to use different caregiving approaches;
- They see the problem some days, but deny it exists on other days.

Here are some statements a parent or caregiver might make when he/she is in the contemplation stage of change:

- *Sometimes I think that his problems might be because I drank during my pregnancy, **but** I know a lot of people who drank a lot more than I did when I was pregnant and their babies are fine;*
- *The descriptions of kids with FASD sound so much like her, but I just don't know how I could live with myself if I knew I had done this to her;*
- *His learning problems could be due to prenatal alcohol exposure, but he could have inherited them from his father, who had the same learning problems when he was a child.*

Here are examples of service provider's responses:

- *So, on the one hand, you think Jennifer's difficulties may be due to prenatal alcohol exposure, but on the other hand, it just seems like too much to deal with right now;*
- *What kinds of things would be supportive to you if you decide to make a change?*

The **service provider's role** in contemplation is to:

- **help the parents or caregivers *tip the scale*** in favour of change by:
 - reflecting both sides of their ambivalence;
 - examining all their reasons for change.
- **normalize the ambivalence** that they feel by reassuring them that their confused feelings are typical;
- **help them move to the preparation stage of change.** Provide information and help them consider the neurological root. Resist the urge to push them to action.

Preparation

This is the stage in which parents or caregivers are intending to take action or make changes in the immediate future. They have a plan of action and are becoming confident in their ability to make their change. Here are some descriptions of people in preparation:

- They have fewer questions about the prenatal alcohol exposure and more questions about how to find ways to help their child;
- They have reached a resolution and are more peaceful, calm, relaxed or settled;
- They express self-motivational statements that show optimism and an openness to seek more information and services for their child;
- They envision life after learning more about the effects of prenatal alcohol exposure on their child, and anticipate difficulties as well as advantages of confirming their child's disabilities.

Here are some statements a parent or caregiver might make when they are in the *preparation* stage of change:

- *I've really thought about it and I know I have to have Jonathan assessed for FASD. I just don't know where to begin;*
- *I've been reading more about FASD, and maybe we should try some different strategies with Mary in the childcare centre. There are so many things in the environment to adapt, and it's hard to know where to start.*

The **service provider's role** in preparation is to:

- **negotiate a plan** that reflects the parents' or caregiver's goals.
- **offer a menu of choice** -- provide as many options for next steps as possible, and allow the parents or caregivers to select those options that they believe will be the most helpful;
- **reduce barriers to change** – provide childcare, transportation, telephone support, referrals, and social support;
- **facilitate observation** – help parents and caregivers observe their child and support them to consider alternative explanations for and interpretations of their child's behaviour and patterns;
- **recognize successes.**

Preparation issues for service providers are:

- give your “best advice” – one step at a time and not too much at once;
- understand resistance;
- don't allow yourself to be discouraged;
- understand the parents' or caregivers' need to take time to prepare to implement their plan.

Action

Action is the fourth stage of change. Here are some descriptions of people in the action stage:

- parents or caregivers are making modifications in their behaviour, environment and interactions with their child;
- they are trying new strategies, and seeing situations differently;
- they are beginning to find their own creative ways to do things differently;
- they face challenging situations and emotions that can surface after they modify their environment, interactions and behaviour.

Some statements that parents or caregivers might make in the *action* stage are:

- *This is really hard. I can't believe how hard it is to find someone who's able to assess Jonathan;*
- *I can't believe the resistance that I'm getting from his kindergarten teacher, who just doesn't understand what he needs;*
- *Our whole family has changed now that we know what Jonathan needs. It's so different to live this way.*

The service provider's role in *action* is to:

- **help parents and caregivers act on the achievable** goals set out in their plan
- **provide positive feedback** for any progress they make on their plan;
- **refrain from negative comments or actions** if they “relapse” or return to old patterns of interaction with the child;
- **help them move** into the maintenance stage of change.

Action issues for service providers:

- address unrealistic hopes and fears;
- reduce or eliminate barriers to the plan where possible;;
- help the family grieve the loss of the hopes that they had had for their child;
- help the family enlist personal and social support.

Maintenance

Maintenance is the fifth stage of change. Here are some descriptions of people in maintenance:

- they work to sustain the progress of their plan;
- parents realize the enormity of the change that is required, and the need to continue to maintain these changes long-term;
- they build in new sources of support for themselves and their child;
- they reflect on their relationship and interactions with their child before recognizing the source of his/her problems, and feel guilt and remorse.

Some statements parents or caregivers may make in the *maintenance* stage are:

- *I feel really guilty about the expectations we had of her before we knew about her prenatal alcohol effects;*
- *We were talking about the strategies we used to use with him before we knew he had FAS, and how that must have been so hard for him.*

The primary **goals for the service provider** in the *maintenance* stage are to:

- **support the changes** that they have made;
- **continue to provide support** either directly or by referral.

Parents in the *maintenance* stage may need the following types of support:

- **emotional support** around feelings of guilt, grief, shame, fear, anger, isolation;
- **emotional support** as the family acknowledges and accepts their child's disability;
- **instrumental support** to access appointments, services, respite;
- **education** about the social context of FASD;
- **education** about parenting strategies;
- **assistance** in observing and understanding the causes of their child's behaviour;

- **assistance** in gathering accurate history and assessments, and to access appropriate services;
- **empowerment** to lead the change process;
- **support** through the frustration arising from not having access to necessary services;
- **support** through the frustration of others not understanding or recognizing FASD.

Remember: FASD may also be an issue for the birth parent.²⁷

²⁷ An examination of the issues related to parenting with FASD is beyond the scope of this manual, but some helpful considerations include: 1) the need for ongoing and comprehensive support; 2) the use of concrete, hands-on approaches; 3) teaching skills in the home, if possible; 4) promoting a quiet, calm environment; 5) providing reminders or environmental cues

SESSION 7:

INTERVENTIONS TO SUPPORT
CHILDREN AFFECTED BY FASD

Session 7: Interventions to Support Children with FASD

Objectives / Outcomes

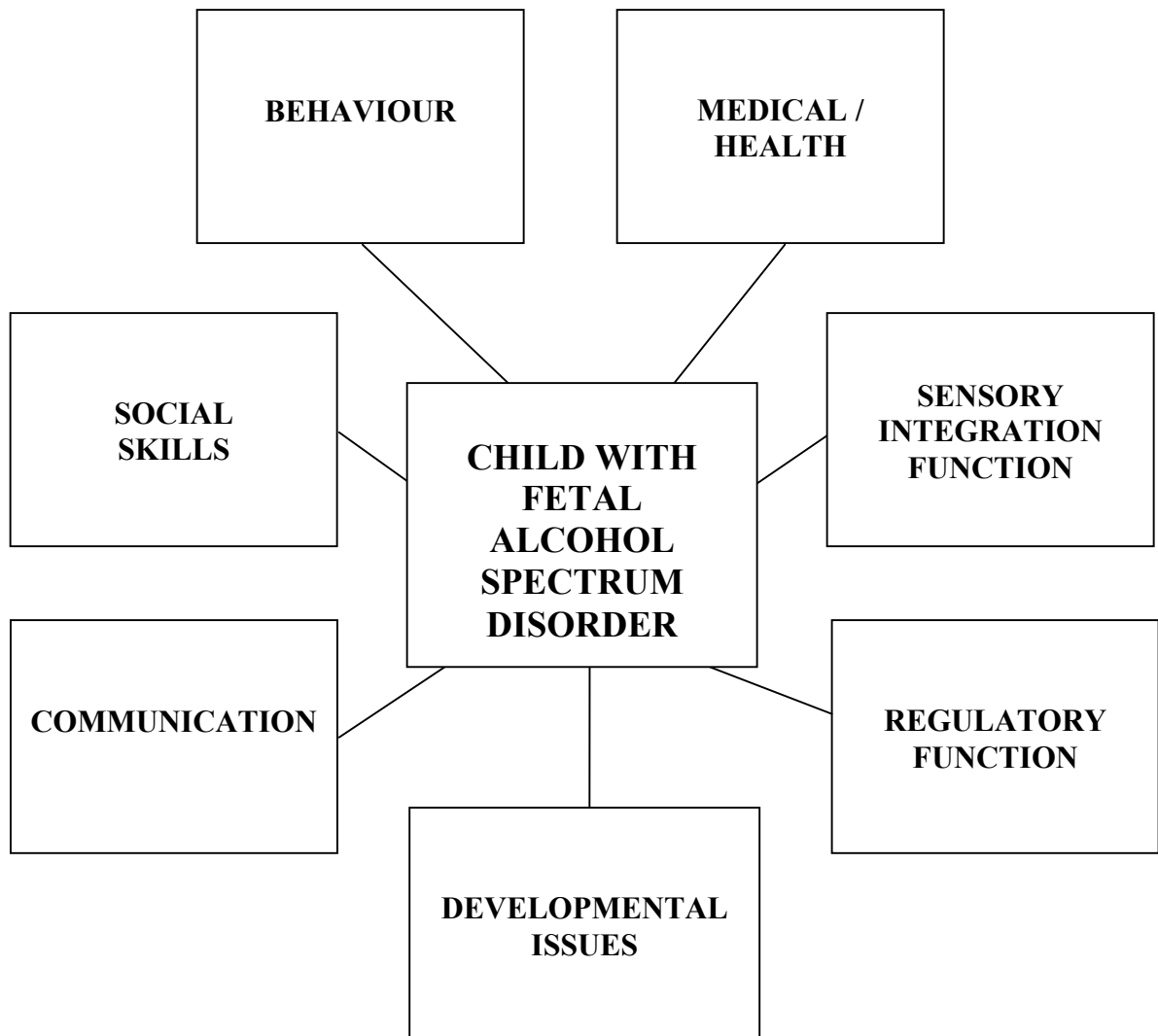
By the end of this session you will:

- increase your understanding of the scope/range of interventions that may be required by a child with FAS;
- increase your understanding of how environments impact children with FASD;
- increase your understanding of how environments can be altered to better support children at home, child care and school.

Key questions

1. Can I identify the range of interventions that are necessary for children with FASD?
2. Can I use a Functional Analysis Tool to better understand the context of behaviour, and recommend appropriate interventions?
3. Can I use the Home Environment Analysis Tool effectively make recommendations for adaptations to the environment?

THE RANGE OF INTERVENTIONS FOR CHILDREN WITH FASD



Interventions for Children with FASD

Introduction

Children who have been prenatally exposed to alcohol may have cognitive, sensory, regulatory, adaptive and/or physical challenges. In considering interventions for a particular child and his or her family, we need a comprehensive understanding of that child's abilities and challenges. Parents, professionals and caregivers all play a role in contributing to a complete understanding of the child.

Here are some important areas for us to know about each child as we develop appropriate interventions:

Medical/Health Status

Children with FASD may have various medical problems. They may have physical anomalies such as skeletal or skin differences that have an impact on their ability to function. They may have congenital problems of organs such as the heart or kidneys. They may be susceptible to viruses or upper respiratory infections that make them more vulnerable when exposed to groups of people. Dental problems are common with teeth that are misaligned or prone to cavities. Vision or hearing impairments are also common. Physical examinations by a doctor, as well as dental, vision and hearing assessments are important components of intervention.

Sensory Integrative Problems

Children with FASD may have difficulty organizing and processing sensory information. When sensory stimulation is experienced by the child as overwhelming, they may shut down; appear anxious, angry or disorganized, or avoidant. Some children have a high threshold for sensory stimulation and they "under-experience" sensory information. They may seek out sensory input by crashing into things, punching, hitting, etc. We can help by recognizing sensory triggers for a child and reducing or increasing the amount of sensory information the child receives. Children with FASD may also have unusually high or low tolerance for pain.

Regulatory Issues

"Self regulation is the ability to attain, maintain and adapt our level of alertness for a specific task or function" (Dorothy Schwab). Children with FASD need a high level of sensorimotor input to sustain their attention. They may also not be able to self-calm. For example, in order for them to stay focused on a task or to self-calm, they may need to use a fidget toy or rock. By providing them with a "sensory diet" that varies from day to day, we may assist the child to feel calm and sustain a level of alertness. Both sensory integrative function and regulatory issues can be assessed by an occupational therapist, who can then recommend interventions.

Developmental Issues

Children with FASD often show uneven developmental abilities and inconsistent performance. For example, their expressive language may be age appropriate but their receptive language or comprehension may be less mature. It is important that we understand the developmental picture as it influences our expectations of children. It can relieve the frustration and change the behaviour of a caregiver to know that a six year old is functioning developmentally at the level of a two or three year old.

Communication

Communication is comprised of receptive language, or what is understood, and expressive language, or what is spoken. The receptive language of children with FASD is dependent upon their ability to listen, remember, sequence and comprehend. Their expressive language or verbal output may be high yet without much content. The assessment of the child's speech language abilities will have an impact on the intervention strategies used by parents and other caregivers. A speech language therapist can be an important member of the team addressing the communication needs of the child.

Social Skills

Social skills are the interactive patterns we use when conversing with others. They consist of the words we use to communicate but also body positions, facial expressions and gestures. Developing social skills requires the ability to take the perspective of others and guess at what others may be thinking.

A child with FASD may not “get” the unspoken rules about social behaviour. They may not read subtle facial cues or other nuances of behaviour that tell us how to behave in a given situation. They might not understand about personal boundaries and move too close. They may speak in a loud voice when the situation requires a whisper. Generally, they can appear “out of step” in a social situations. This has a tremendous impact on the acceptance of a peer group.

Behaviours

Children with FASD may show such behaviours as impulsivity, distractibility, inconsistent performance, memory problems, difficulty with transitions, difficulty with forming associations, generalizing, abstracting and predicting. These behaviours may reflect brain or neurological function.

After we have determined that a child's difficulties are not due to health/medical reasons, or hearing and vision impairments, we need to explore the context of the behaviour.

The Context of Behaviour

Understanding the neurological problems seen in alcohol-exposed children involves determining the degree to which the problems can be attributed to the exposure to alcohol in utero, to the effects of environmental factors such as parenting functioning, home environment or placement stability -- or to some combination of the two. At present, there is no easy answer to this question. Because children develop within a family and a community, their caregiving environment must be given careful consideration in understanding their behaviour and development.

In situations where children have neurological damage that limits their ability to change, interventions must focus on adaptations to the environment: the social as well as the physical environment. An intervention plan for children who are affected by prenatal alcohol exposure must consider the context in which the behaviour occurs.

Remember: If a child does not have the capacity to adapt to the environment, then the onus is on the environment to adapt to the child.

Here are two tools that can be used to understand the physical and social contexts in which behaviour occurs, and help us to make adaptations to the environment to change behaviour and support children with FASD:

1. Functional Analysis
2. The Home Environmental Assessment Tool

1. Functional Analysis Tool (See Session #4)

The functional analysis tool, described in Session #4, can be effectively applied to understand the context of behaviour of children who are affected by prenatal alcohol exposure.

The purpose of a functional analysis is to:

1. Identify an observable pattern to a child's behaviour and identify the neurological effects that may underly the behaviour;
2. Identify environmental factors influencing a child's behaviour;
3. Assess the effectiveness of caregiver's responses to the child's behaviour;
4. Generate strategies that will support the child and caregiver in these situations.

Conducting the Functional Analysis

In conducting the functional analysis, information is generated by interviewing caregivers and/or direct observation of the child:

1. Interviewing appropriate caregivers:

- Parents;
- Child care providers;
- Teachers;
- Others.

i. *Ask caregivers to clearly describe the challenging behaviour the child is demonstrating.*

ii. *Ask what happens just before or right at the time the behaviour usually occurs.*

During free play, when asked to clean up, while sitting at circle time, when getting ready to go outside, while getting ready for bed.

iii. *Ask where this is taking place – in which environmental context.*

While on a field trip, while out shopping, at child care or school.

iv. *Ask how the behaviour is responded to or what strategies are currently being used.*

Redirection? Reminders? Time out? Breaking down steps of a task? Physical removal of the child? Provide movement break?

v. *Identify the neurological deficits that are impacting the child's behaviour.*

Sensory overload? Regulatory difficulties? Planning in new situations?

2. Observing the child in the environment where problems are arising.

Ideally, it is helpful to observe the child in all the environments in which the behaviour appears to be a problem, and to observe the child on more than one occasion in each environment. Be sure to note the precipitating event or environmental factors influencing the behaviour, and the caregivers' response to the child's behaviour.

The functional analysis tool should be completed following the collection of the information from caregiver interviews and observations. A clear pattern to the child's behaviour in response to the environment usually emerges, and gives us a better understanding of how to change or adapt the environment in order to change the behaviour and support the child.

Use one template for each behaviour being examined.

Functional Analysis and Adaptations/Strategies

Child's Name:

Date:

Circumstances:

(What was happening, time of day, activity taking place, where did behavior happen, etc.?)

Behavior:

(What challenging behavior was taking place?)

Current Response:

(How is the behavior currently being responded to?)

Elements of Circumstances	Adaptations/Strategies
(What environmental factors are influencing the behavior? What aspect of the disability is creating difficulty? What is the behavior communicating? What is the impact of sensory information – tactile, visual, auditory and proprioceptive stimulation)	(What strategies and adaptations and supports can be implemented to respond to the elements identified?)

Comments: (follow up, outcome, child's reaction to strategy, etc)

Learning Activity #8: Case Scenario with Functional Analysis

The purpose of this learning activity is to gain experience in completing a functional analysis based on a case scenario.

You will be asked to complete the functional analysis below by generating additional antecedents and effects (consequences) of the behaviour that is being examined. You will also be asked to think of adaptations to the environment or to caregiver responses that might prevent or change the behaviour and support the child. The facilitator will debrief the exercise in a large group discussion.

Case Scenario – Katie

Katie and her family have been referred to you for assistance in understanding Katie's behavioral difficulties and how they should intervene to best support her. Katie is five years of age and has a diagnosis of Partial Fetal Alcohol Syndrome. She is attending a childcare centre on a full time basis, with special needs support. Katie's parents and the childcare providers have identified a number of concerns around Katie's behavior. Her parents report that Katie has temper tantrums (including yelling, screaming, refusing to cooperate/ignoring verbal requests and hitting) whenever they go grocery shopping or to the mall. They report that she also tantrums when they have company over. Katie's parents also indicate that she has difficulty when preparing to go leave home or leave the childcare. During these times, they report that Katie runs around, refuses to comply with requests to get ready, yells and cries. Preparing Katie for bath time is also difficult for Katie, and results in behaviours such as refusing to cooperate/ignoring verbal requests, yelling, screaming, hitting and kicking.

Katie's parents usually respond by telling her to stop, by repeating their requests, by giving mini lectures to Katie, and by placing her in time out.

The childcare staff identified difficulties at the following times:

- getting ready to go home -- similar behavior challenges identified by family;
- during free play time -- wandering, yelling and hitting other children, isolating herself;
- at clean up time -- wandering, refusing to pick up toys;
- getting ready to go outside and to come back in -- slow pace, pushing other children, yelling;
- lunch time -- difficulty remaining seated after eating her lunch, wandering away from the table, pushing and poking other children.

The child care staff usually responded to Katie's aggressive behavior and repeated incidents of non-compliance by physically removing her or placing her in time out. For lesser incidents they usually gave her verbal reminders, told her to stop and talked to her about her behavior (mini lecture).

Answer Key for Learning Activity # 8

The following are a list of antecedents that may be identified from the Katie scenario, and recommendations for interventions:

Transitions: Provide structure, routines, preparation for change and assistance with transitions using sand timers, kitchen timers, transition songs/music, and picture symbol schedule board.

Unstructured Time: assist with organization or planning; provide two choices of activities for her to choose from; help her start an activity, read warning signs and be available when needed.

- **Increased Noise Levels:** Avoid these environments if possible or limit her exposure to them; provide Walkman with favorite songs while in malls to block out overwhelming noise; adapt the environment by reducing noise when possible;
- **Over-stimulating Environments:** Provide a quiet/calming space (bean bag chair, pillow and blanket, tent), reduce visual stimulation and clutter;
- **Difficulty Planning and Organizing:** Provide visual cues, break steps down (“first we will do this, then we will do that”), use concrete language, limit choices to two, repeat instructions, and provide assistance through modeling;
- **Changes in Routine:** Prepare for changes; give notice that something different will be happening (see transitions);
- **Processing Auditory Information:** Allow extra time for processing, (see organization and planning);
- **Difficulty Focusing and Attending:** Allow for movement breaks, provide fidget items, redirection to calming space;
- **Sensitive to touch/personal space:** Designate an area where Katie can get dressed to go outside where she is less likely to get pushed or bumped; use carpet squares at free play time in order to establish personal boundaries/play areas; let her be the first or last in line (limits chances of becoming bumped from behind);
- **Difficulty in Social Situations:** Model turn taking and sharing; incorporate a buddy into free play time where opportunity for turn taking is present; provide a lot of praise and positive feedback.

Interventions that have not worked with Katie:

- repeating instructions; ignoring behaviour; lecture; time out

Learning Activity #9: Home Environment Analysis Tool

The Learning Activity

In small groups of three or four, you use the Home Environment Analysis Tool (pg. 80), and the visual image of Jimmy's bedroom (pg. 84) to prepare recommendations to better accommodate Jimmy. You will have about 30 minutes to develop your recommendations. Recommendations from each group will be fed back in a large group discussion.

Case Scenario: Jimmy's Bedroom

Nine-year old Jimmy and his family were referred to your program by his pediatrician to for support and intervention regarding his sleep problem. His parents are frustrated because it has become increasingly difficult for Jimmy to fall asleep at night. It is now taking him up at least 2 hours to fall asleep. Jimmy is exhausted and his parents are frustrated.

Jimmy's mother acknowledges that she used alcohol when she was pregnant with Jimmy, in order to cope with the stress in her relationship with Jimmy's father. Jimmy's parents admit that he has always been "more than a handful". His energy level leaves them exhausted at the end of each day. His teacher's concerns about his lack of attention, disregard for instructions, and constant interruption of the other children's work has them worried.

Jimmy's parents have just re-decorated his bedroom. They framed posters to cover most of the wall space. They added a halogen desk lamp to the fluorescent lighting on the ceiling. The window is covered with heavy drapes and a blackout blind, as Jimmy cannot sleep with even a hint of light in the room. The drapes are never opened because it is too difficult to get them back into position. Although Jimmy has had a night light in the past, his parents removed it because "nine year old boys are too big to be afraid of the dark".

Jimmy's parents bought a new bed, sofa, tables, dresser and rugs in primary colours. The open shelving unit is piled high with books and toys. The toys that do not fit in the shelves and are left on the floor and sofa. The desk is his space for homework.

The table surfaces are covered with books, toys, crayons, and paper, and clothing is left on the floor and sofa. Jimmy's mother constantly reminds him to clean his room but she says he "ignores" her. She asks him daily to make his bed, he can't seem to get the sheets and blankets smoothed out. Jimmy's clothes are stored in his dresser and closet. When he puts his laundry away, he tries to cram as much as possible into the deep, bottom drawer of the dresser. He often cannot find the clothes he needs in the morning.

Home Environmental Analysis Tool

(complete in a structured interview format and/or during environmental observation with family)

Date: _____

Name of Child: _____

Date of Birth: _____

Name of Parent: _____

Address: _____

Phone: _____

SECTION A: PHYSICAL ENVIRONMENT

Identify space: _____

Consider the following issues when observing this space:

- Colour
- Lighting
- Sound
- Smells
- Size of space
- Furniture, equipment / amount and arrangement
- Boundaries and traffic flow

SECTION B: FAMILY/CHILD ROUTINES FOR THIS SPACE

1. What activities take place in this space?

2. What are the parental expectations of the child when in this space?

3. What difficulties does the child have when they are in this space?

4. Why might they have these difficulties?

5. What changes would you make to the environment to better accommodate this child? How would these changes help?

Jimmy's Bedroom



Learning Activity #9: Answer Key for Home Environmental Analysis Tool

Description of Physical Space:

Colour

- Neutral taupe walls may have calming effect;
- Bright primary colours in posters, furniture, rugs, toys.

Lighting

- Fluorescent light is harsh and often has buzzing noise when on;
- Halogen can also be hard on eyes;
- Natural light is not used due to difficulty in getting window blacked out at night.

Size of space

- Bedroom is a large space as accommodates bed, sofa, desk, dresser and shelves.

Furniture and equipment / amount and arrangement

- This is a big room but there is also a lot of furniture in it;
- Although the desk is somewhat delineated by chair facing it, there are no clear boundaries between bed and activity table, or between the bed and sofa;
- The activity table in middle of room blocks traffic flow to desk, sofa, shelving, dresser and closet.

What activities take place in this space?

- Sleeping;
- Dressing and undressing;
- Homework;
- Playing with toys, colouring, drawing, reading books;
- Entertaining friends;
- Relaxing.

What are the parental expectations of the child when in this space?

- All of the activities above;
- To get to sleep quickly without a nightlight;
- To do chores – make bed, put away clean laundry, put dirty laundry in bathroom hamper;
- To play contentedly;
- To want to spend time in the bedroom.

What difficulties does the child have when they are in this space?

- Can't get to sleep;
- Can't keep it neat;
- Can't find his clothes when its time to dress;
- Difficult to get bed made neatly;
- Doesn't want to play there;

What changes would you make to the environment to better accommodate this child and why?

- Replace fluorescent lighting with incandescent lighting to reduce the harshness of overhead lighting and thereby reduce the stress and over stimulation associated with fluorescents;
- Access the natural light from the window in the room by adding a blackout panel to the drapes and eliminating the need for the blind;
- Remove some of the posters from the walls;
- Reduce the amount of furniture in Jimmy's room;
- Organize toys so that each one has a place to be put away;
- Cover the storage shelving to hide toys and other distractions when Jimmy is focusing on homework or trying to get to sleep;
- Remove half of the toys and store them away. As Jimmy gets bored with the ones in his room, they can be rotated with the ones in storage;
- Get rid of superfluous objects in the room such as rugs, throw pillows and stuffed animals (except for his favourites);
- Put visual symbols on the dresser and closet door that remind Jimmy where clothes are stored. A picture of socks can be taped to the sock drawer, pants to the pant drawer, and so on. This will make it easier for Jimmy to put clean laundry away and find his clothes when dressing in the morning;
- Change the bedding on Jimmy's bed so it is easier to make. A quilt or duvet can simply be pulled up to cover the entire bed. Examine the weight of bed coverings: does Jimmy prefer light covering while sleeping or weighted blankets?
- Discuss expectations with Jimmy's parents. Is Jimmy younger than his years? Are his tantrums and need for a night light perhaps indicative of his "dysmaturity"?
- What is Jimmy's bedtime routine? He is a child who needs time to anticipate the change and switch gears. Does he have enough time to transition from activity to bed? Are there activities (e.g. a warm bath, a story time, quiet music) help to wind down to bedtime? Is there a ritual for saying good night?

SESSION 8:

Advocating with Children Affected by FASD and their Families

Session 8: Advocating for Children and Families Affected by FASD

Objectives / Outcomes

By the end of this session you will:

- develop skills to advocate for families with children with FASD;
- understand the differences between *collaborative* and *confrontative* styles of advocacy.

A key question

- Am I able to use effective advocacy approaches on behalf of children and families affected by FASD?

Advocating for Children and Families Affected by FASD

Advocacy means speaking on behalf of another person. Advocacy can involve: interpreting behaviour; mediating among providers; accessing services.

Effective advocacy involves:

- **educating yourself** with sound, factual knowledge of FASD;
- **understanding difficulties** a child has related to FASD, how these difficulties interact with developmental stages, and any other issues facing the child, e.g. disrupted attachment;
- **building strong relationships** and partnerships with staff at other agencies, remembering that FASD is a lifelong disability requiring advocacy for services from many systems throughout the lifespan;
- **educating staff** in other agencies so they will become advocates for children with FASD - this process unfolds over time, as you gently nudge other agencies and workers to shift their perspectives of the needs of children with FASD; in time, this also builds capacity in other agencies to more effectively meet the needs of clients living with FASD;
- **recognizing ‘poor fit’** between needs of children with FASD and the services they may need;
- **recognizing** the unevenness of the strengths and difficulties displayed by children with FASD and that this may lead to misunderstandings that you must help to mediate;
- **avoiding conflictual tactics** that can damage relationships and, instead, operating as collaboratively as possible;
- **being appreciative** recognizing that one day you may be asking a huge favour of the other agency or asking them to really push the limits of their policies;
- **problem solving** with everyone involved using this mnemonic:
 - R**ecognize the problem
 - E**xplore the nature of the problem in detail
 - S**tate the problem clearly
 - O**bserve and gather information
 - L**ist possible solutions
 - V**enture forward: pick one solution and try it out
 - E**valuate how the solution worked

The following are two advocacy models:

Collaborative advocacy is a relational way of advocating. The advocate uses good communication and conflict resolution skills to build relationships with other parties, acknowledges the other system's point of view (agency mandates or policies that constrain the worker's ability to respond to requests), and will usually result in better long-term results. Workers in other systems come to respect and value the input of the advocate and are therefore willing to work inside their own system to access resources. Workers gradually learn from the advocate what FASD means to an affected child and his/her family and become more able to respond to all requests for help from families dealing with FASD, thereby effecting wider community change.

Confrontational advocacy uses leverage from laws, policies, or threatened action. This approach may on occasion result in quicker short-term results, or shift a completely rigid situation. However, there are also frequent negative consequences that should be considered. This type of approach frequently damages relationships, fails to educate or transfer knowledge to the other system, and may damage relationships with other partner agencies or staff who do not wish to be associated with highly conflictual tactics. FASD is a life-long disability. Advocating for families of individuals with FASD is an ongoing process for everyone who works with these individuals and their families. It is unproductive to risk damaging relationships or the good will of agencies that provide services for these individuals. Workers on the receiving end of conflictual tactics are likely to become less willing to respond in the future to your requests or to those of other advocates. Many restrictive rules and regulations are created followed unpleasant incidents. Use of such tactics should be considered only as a last resort, following in-depth consultation with co-workers, supervisors, partner agencies, and consultation with experts such as lawyers or social workers.

These are steps to consider when preparing to advocate on behalf of a child and family:

- **Seek permission.** Make sure the family is aware of any potential negative consequences that could arise as well as the positive benefits hoped for before they agree to your advocating for them;
- **Be realistic.** Be clear with families about possible outcomes. Do not promise anything; instead, offer to try and effect change on their behalf;
- **Prepare yourself.** Work through your own issues regarding prenatal alcohol use, and any other issues that would make it difficult to advocate in a calm, clear, sensitive, and respectful manner;
- **Educate yourself.** Develop a good knowledge base regarding FASD;
- **Understand your community.** Develop an understanding of programs, services, and systems in your community. Learn how the Stages of Change Model applies to the level of readiness in your community to respond to FASD;

- **Understand the perspective of other service providers.** Learn how the Stages of Change Model applies to a paradigm shift when it comes to understanding FASD. Learn to apply the Stages of Change approach to service providers in terms of their perspective of the child with FASD (e.g., service providers who believe the behaviour of a child with FASD is wilful misbehaviour rather than a result of organic brain damage may present an advocacy challenge with respect to changing their way of disciplining the child).

The focus for advocacy is centred on:

- **Adaptations to the environment** (at home, day care, school, etc.) so that the child with FASD can function more appropriately;
- **Adaptations to caregiver interactions** that include a planning process for upcoming transitions (e.g. moves to new programs or to a new foster home), discussing future events or changes well in advance so the child is prepared and has time to get used to the impending changes, and brainstorming different ways that caregivers can interact with the child to better meet his/her needs (e.g., give extra time, simplify directions, use visual cues);
- **Anything that is needed by the family**, including access to services, adaptation of services, modifications of rules and policies that do not support children with FASD, etc.

Learning Activity # 10: Self-correcting T/F test: Collaborative versus Confrontative Advocacy

The purpose of this activity is to confirm and extend your understanding of collaborative and confrontative advocacy approaches. Questions or comments will be discussed as a large group following completion of the self-correcting test.

Advocacy Self Correcting Test

For each of the following decide if this is a **collaborative (L)** or **confrontative (F)** approach and circle the appropriate letter.

1. *I would like to recommend that you make a schedule using photographs of Jimmy to help him know what he will be doing each day, what is coming next, and so on. How can I help you set this up? (L / F)*
2. *I am really concerned that Mary is getting so upset when she is dropped off to Day Care each morning and picked up each evening. I'm wondering what we could do to make this transition easier for Mary. (L / F)*
3. *Annie needs a one-on-one worker right now. If you don't have one in place by next Monday, I shall be calling your supervisor and reporting you for not doing your job. (L / F)*
4. *This family is in desperate need of respite. The mother is on antidepressants which will take a couple of weeks to work. She cannot manage to care for her four children (aged 6, 4, 3 and 6 months) by herself all day long. She is particularly having difficulty with her three year old who has FASD. He is very upset that his father is no longer living with the family, and now his mother is not really available to him because of depression. Changes really upset him, and he is getting really angry hitting, kicking, and biting his mother and his siblings. The mother becomes more and more depressed, feeling she will never be able to manage her son. I know respite workers are hard to get, but I really feel this family needs to be given top priority to prevent either the family breaking down or one of the children being hurt. Is there anything you can do to get emergency respite for this family? I would really appreciate anything you can do. (L / F)*
5. *This family really needs respite right now. I have already called the provincial child advocate, and the executive director of your agency because I know your agency never gets families what they need. I expect a respite worker to be on the job tomorrow morning or I shall be making further calls and you will be losing your job before you know it. (L / F)*

6. (Phone call to a Clinic that diagnoses FASD regarding a child on the wait list for diagnosis who is having some difficulties in school). *This is a medical emergency. This child must be seen this week or there will be serious consequences. Call me with an appointment today.* (L / F)

Advocacy Self-Correcting Test**Answer Key**

1. COLLABORATIVE (L). This is phrased as a tentative recommendation, and there is an offer to help and collaborate with the service provider.
2. COLLABORATIVE (L). There is a clear statement as to what the difficulty is about, and an invitation to engage in collaborative problem solving with everyone involved in the conversation.
3. CONFRONTATIVE (F). There is a clear statement of what is needed, but the words 'right now' suggest the speaker is being demanding. This is followed by a threat (If you don't . . . , I will . . .) which may cause the recipient to respond defensively, and with anger. This kind of approach may make the original problem more difficult to solve, because the ensuing conflict with the other worker will divert energy from solving the problem and building good working partnerships with the other agency.
4. COLLABORATIVE (L). There is a detailed description as to why this situation is urgent and requires an out of the ordinary response. There is recognition that what is being requested (emergency respite) is not easy to provide, and an explanation of the possible logical consequences if no one is able to act. The request for services is still tentative and respectful of the other worker. There is an acknowledgment that any effort will be appreciated, which may help engage the other worker to put forth their best efforts to see if they can mobilize their agency to help out this family.
5. CONFRONTATIVE (F). This request is for the same family as question #4. The other worker has no idea what the difficulty is or why he or she should consider going beyond the usual policy of their agency (e.g. There is a 6 month waitlist for respite; this family will have to wait like everyone else.) The advocating worker has attacked this worker's agency and has already made calls to people in positions of power which may make the worker receiving the call feel quite threatened and angry (see #3). There is no tentativeness to this caller's request, and the caller has determined that success will be services provided tomorrow. There is no room for problem solving or collaboration. The agency worker is unlikely to feel like going out on a limb and advocating within their own organization to make something unusual happen.
6. CONFRONTATIVE (F). This is a classic case of 'crying wolf', which -- as the original story would suggest -- is never a wise thing to do. Claiming a medical emergency when it does not exist will damage your credibility with service providers in future requests of this nature.

Appendix A: References for further study

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APPENDIX B:**Canada Prenatal Nutrition Project (CPNP)**

CPNP funds community groups to develop or enhance programs for vulnerable pregnant women. Through a community development approach, the CPNP aims to reduce the incidence of unhealthy birth weights, improve the health of both infant and mother and encourage breastfeeding.

CPNP enhances access to services and strengthens inter-sectoral collaboration to support the needs of pregnant women facing conditions of risk. As a comprehensive program, the services provided include food supplementation, nutrition counselling, support, education, referral and counselling on health and lifestyle issues.

There are currently 350 CPNP projects funded by Health Canada's Population and Public Health Branch serving over 2,000 communities across Canada. In addition, over 550 CPNP projects are funded by the First Nations and Inuit Health Branch in Inuit and on-reserve First Nation communities.

CPNP targets those women most likely to have unhealthy babies due to poor health and nutrition. Over 95% of projects target pregnant women living in poverty, teens, or women living in isolation or with poor access to services. Other client groups targeted include women who abuse alcohol or drugs, live with violence, women with gestational diabetes, Aboriginal women, and immigrant and/or refugee women.

Community Action Program for Children (CAPC)

CAPC provides long term funding to community coalitions to deliver programs that address the health and development of children (0-6 years) who are living in conditions of risk. It recognizes that communities have the ability to identify and respond to the needs of children and places a strong emphasis on partnerships and community capacity building.

CAPC projects provide parents with the support and information they need to raise their children. CAPC targets children living in low-income families; children living in teenage-parent families; children experiencing developmental delays, social, emotional or behavioural problems; and abused and neglected children.

Special consideration is given to Métis, Inuit and off-reserve First Nations children, and the children of recent immigrants and refugees, children in lone-parent families and children who live in remote and isolated communities.

There are 464 CAPC projects across Canada.

Appendix C: Project Managers

Mothercraft (Breaking the Cycle)

Mothercraft is a charitable organization and a leader in the promotion and support for healthy child development. Among the important programs that Mothercraft sponsors is Breaking the Cycle (BTC). Established in 1995, BTC is a community-based early identification and prevention program designed to reduce risk and enhance the development of substance-exposed children (prenatal to 6 years) by addressing maternal addiction issues and the mother-child relationship through an integrated, cross-sectoral model. Funded by Health Canada's CAPC and CPNP programs, BTC operates through the efforts of a partnership that includes Mothercraft, the Jean Tweed Centre, the Motherisk Program – Hospital for Sick Children, the Children's Aid Society of Toronto, the Catholic Children's Aid Society of Toronto, Toronto Public Health, and St. Joseph's Health Centre. Comprehensive services are offered through a single-access model in which mothers and children may access addiction, health, developmental and parenting services, and basic needs supports through an integrated, trans-disciplinary approach in a community-based location in downtown Toronto. The model is augmented by a pregnancy outreach service that supports and engages pregnant, homeless women using substances.

Breaking the Cycle has engaged in a range of knowledge transfer projects through consultation, training, and resource development. Involvement in a number of FASD activities have led to the development of resources including:

- Enhancing Fetal Alcohol Syndrome (FAS)-related Intervention at the Prenatal and Early Childhood Stages in Canada;
- Different Directions: Understanding Fetal Alcohol Syndrome - A Train the Trainer Manual, and three accompanying training videos ("Different Directions: Understanding FAS"; "Different Directions: Community Prevention"; "Different Directions: Early Interventions in FAS");
- The SMART Guide: Motivational Approaches Within the Stages of Change for Pregnant Women Who Use Alcohol.

Canadian Centre on Substance Abuse

The Canadian Centre on Substance Abuse is Canada's principle national NGO addressing substance abuse. Established by an Act of Parliament as an arm's length organization, the Centre's mandate is to lend support and leadership to activity preventing and reducing the harms associated with substance abuse. Funded by Health Canada, the Solicitor General and through its own revenue-generating efforts, the Centre:

- Promotes informed debate on substance abuse issues and encourages public participation in reducing the harm associated with drug abuse;

- Disseminates information on the nature, extent and consequences of substance abuse;
- Supports and assists organizations involved in substance abuse treatment, prevention and educational programming.

The Centre is engaged in the development of best practice advice, guidelines for treatment and rehabilitation, tobacco cessation, youth prevention, and practices pertaining to FASD and other substance use and pregnancy issues. The Centre provides support to the public, parents and practitioners on substance use and pregnancy issues through its FASD Information Services and the Online FASD Tool Kit.