Empowering Front-Line Staff and Families Through a Collection of Lived Experiences

College of New Caledonia

Supporting women who have Fetal Alcohol Spectrum Disorder (FASD) behaviours and characteristics and/or other related disabilities

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Anne Guarasci, Writer

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Background

This resource was developed as a result of recommendations from Canada Prenatal Nutrition Program (CPNP), Community Action Plan for Children (CAPC) and Aboriginal Headstart Program (AHS) frontline workers and coordinators (PHAC 2010) for stories that help bring clarity to the issue of FASD. These programs target families with children from 0 to 6 years of age who are considered to be at risk. Many program participants struggle with poverty, unemployment, unstable living conditions, violence and substance dependency. They may also have difficulty with relationships and parenting.

This document is intended to assist CPNP, CAPC and AHS workers and coordinators across BC in working effectively with parents who display FASD like behaviours and characteristics.

As knowledge of FASD has increased over the years, frontline workers have observed FASD like behaviours and characteristics in many parents who access programs. These behaviours can be confusing and leave workers unsure as to how they can best respond. Stories have been cited as invaluable in assisting workers in understanding how FASD may present in frontline work and illustrating what they can do differently to accommodate participants who have FASD or other related disabilities.

Stories and examples were contributed by outreach workers, group facilitators and caregivers primarily from BC's northern interior region although several stories were also contributed from BC's interior, and Vancouver Island. It is anticipated that workers in programs may recognize aspects of these stories in the lives of their participants.

This document is offered as a resource and is intended to help build capacity of CPNP, CAPC and AHS programs in BC to meet the needs of families who live with FASD by:

- Providing real life stories about marginalized women who may have FASD
- Assisting frontline workers to recognize behaviours associated with FASD
- Demonstrating the complexities associated with marginalized women who live with FASD
- Identifying potential strategies and promising practices for working with and supporting families.

This document is not meant to be prescriptive and does not provide definitive strategies or approaches.

In Recognition of the Women Who Access Our Programs

Parenting is challenging for everyone. Babies and young children need constant support, caring and supervision. Parenting can be exhausting, confusing and overwhelming, even for the most well balanced and supported caregiver.

Many of the women who access our programs are pregnant and/or parenting, but in addition to the challenges faced by every parent they cope with a variety of social challenges including extreme poverty, violence, trauma, depression, addiction and isolation. They often have FASD - related characteristics and struggle with organization, time, money, relationships and parenting. Very few are diagnosed, and generally, support is limited or nonexistent, making each day a challenge to figure out a world that is not designed for their reality.

FASD is an incredibly complex disorder that manifests in a myriad of ways. Early prevention campaigns focused entirely on changing women's drinking patterns with the view that FASD prevention is simple. Currently there is more understanding about the complex issues around prenatal alcohol exposure. Alcohol use is largely socially accepted and alcohol misuse is often encouraged yet in our society some are quick to vilify women who unintentionally, or through addiction, consume alcohol during pregnancy.

Through this document we hope to shed light on the strengths and resourcefulness of the women who participate in our programs. These women demonstrate tenacity in the most dire circumstances. They are dedicated to their children and desire to parent to the best of their abilities. They face tremendous challenges and barriers and yet work hard to build healthy support networks by participating in parenting groups and support programs where they talk and laugh together.

Workers are encouraged to practice from a place of utmost respect for the parents and children who are living with FASD. It is from them, and their stories that we learn the most about how the complexity of FASD affects each and every part of their lives.
From these amazing women we learn the importance of accepting differences and the need for increased understanding. Their willingness to work together and to learn is a tribute to their commitment and strength. They set an excellent example of courage and perseverance, and it is an honour to be a part of their lives.

One of my clients found that if she breastfed her baby her friends were less likely to pressure her to drink. She had abstained from alcohol most of her pregnancy and wanted to continue to avoid it so she nursed her daughter for 18 months!

Outreach Worker

A Collection of Lived Experiences and Stories

The following stories were contributed by workers, facilitators, coordinators and parents of adult women who have an FASD diagnosis and/or FASD behaviours and characteristics. The stories are focused on pregnant and parenting women who access programs. This is not meant to minimize the importance of working with men but reflects the fact that few programs are funded and designed to meet the needs of men, hence, we have limited experience working with men.

These stories are real experiences of women in our programs. Names and inconsequential details have been changed for anonymity. At times it may be difficult to determine whether or not a disability exists for a woman especially if she does not have a diagnosis which is usually the case. Services need to be individualized and based on a trusting relationship. This allows the support worker and/or facilitator to observe behaviours and develop appropriate interventions.

Developing a trusting relationship requires that workers approach clients with respect and understanding. Workers need to let go of preconceived notions and avoid unrealistic expectations or unnecessary limitations so they can set participants up for success. Even small successes can be powerful and they help workers understand the value of the support.

Supporting marginalized women who have FASD behaviours and characteristics is complex and usually multiple issues are happening at the same time. Uncovering these issues and teasing out what is attributed to FASD and what is attributed to poverty, trauma or addiction is challenging. In addition, individuals who have FASD can be inconsistent in their abilities, so they may be able to function and complete tasks for a while and then forget what to do and be unable to perform those same tasks.

Amanda

Amanda was 17 when she gave birth to her daughter. At the time Amanda lived with her sister in a crowded apartment with very little privacy. In spite of the health nurse's efforts to encourage Amanda to nurse her baby, she chose to bottle feed – she was embarrassed to nurse her baby "in front of all those people".

The nurse referred Amanda to an outreach program that offered weekly parenting classes. Amanda connected well with her outreach worker who liked to visit her at home. Amanda could not understand the directions for preparing formula and consistently put too much powder in each batch. As a result the baby was having digestive problems.

Amanda's outreach worker worked alongside her to show her how to measure the powder and water. They developed step-by-step instructions and drew lines on the containers to assist with measuring. They made formula together several times until Amanda was able to do it herself.

Amanda fed the baby correctly for over a month and then it seemed "out of the blue" that she forgot how to make the formula properly and once again was putting too much powder in the bottle.

The outreach worker recalled that she had supported Amanda to acquire an apartment of her own in that period of time. Amanda could not remember how to make formula in her new apartment.

What's Happening

Amanda is trying her best to take care of her baby. She is young developmentally and feels too uncomfortable to nurse her infant. Her living conditions were uncomfortable but she didn't know how to change them on her own. She is able to learn how to make formula properly, with support but she could not generalize the information she learned about making formula from her one apartment to another.

Potential Strategies and Supports

Amanda requires support to navigate systems (housing) and to complete complex tasks such as preparing formula. Tasks that require a multi step process need to be broken down into easy to follow steps.

When things seem to go awry it's important to approach the situation with curiosity. Amanda needed to be re-taught how to make formula in her new surroundings.

Maggie

Maggie participated in a pregnancy outreach program. With the support and understanding of her outreach worker and her group facilitator, she was able to maintain a healthy pregnancy. She and her support worker made regular appointments with health professionals to ensure that her son was healthy and gaining enough weight. Maggie had challenges with organization. When her support worker came to pick her up for appointments the baby would be bundled up and ready to go but Maggie would still be in her pyjamas and had not eaten breakfast.

Maggie would become irritated with her support worker because she wasn't ready to go. Maggie's worker remained calm. She informed Maggie that the baby would probably get too hot if he stayed in his snow suit until Maggie was ready. Then she asked Maggie if it would be okay to take the baby out of his snowsuit and play with him while Maggie got ready.

After the appointment they returned to Maggie's apartment and the worker suggested they make a list of things to do when getting ready to go out in the morning. They worked together on the list and Maggie drew illustrations beside each point. She tacked the list on the inside of her door so that when she wanted to go somewhere it would be easy to find.

What's Happening

Maggie knows that she needs support and she wants to do the best she can for her son. Her challenges with organization have to do with her inability to determine how tasks should be sequenced.

Maggie becomes frustrated and has a tendency to lash out at her worker – she could be feeling rushed or she may be embarrassed because she isn't ready to go. She may also have difficulty with impulse control and/or she may feel that appearing angry at her worker is better than looking "stupid".

Potential Strategies and Supports

Like everyone, Maggie needs to feel valued and respected. It's important to not take Maggie's frustration and outbursts personally and to maintain a non -judgmental and supportive approach. Once Maggie has had a chance to settle down, the time is right to engage her in problem solving.

Maggie will require similar support for chores that require a sequence of events such as laundry, cleaning, bathing her baby and grocery shopping. Working together with Maggie to develop step by step instructions and allowing her to draw corresponding illustrations is an effective method to support her to function on a daily basis.

Vera

Vera has a three month old baby and a three year old toddler. She has been attending a parenting group for the last six months. The group focuses on good nutrition and has been involved in a community garden. Vera has never gardened before and she was very excited when she first saw her vegetables growing.

It was late summer and the time had come to harvest some of the vegetables. Vera noticed that most of her carrots had disappeared. She was visibly upset and talked to her facilitator about the missing carrots. Vera continued to express concern about not being able to understand who would do such a thing or why anyone would take her vegetables.

The worker recognized Vera's frustration, she expressed empathy, and explained that possibly the person who took her carrots didn't understand he or she was stealing or maybe that person was hungry. This explanation did not ease Vera's distress. She could not understand why this happened and she was unable to stop thinking or talking about it and seemed to be getting more and more upset.

Eventually the facilitator asked Vera if she would like to go out for a cup of tea. They decided to walk and since talking about the carrots seemed to distress her more, the worker started talking about Vera's incredible ability to draw cartoon pictures. She asked Vera if she would consider drawing an illustration of a car seat for a workshop poster. Vera's mood lightened and she was flattered that her worker wanted her to help with a project. Her concern about the carrots melted away.

What's Happening

Vera was perseverating and was unable to move on to another topic without support. She may be taking the situation personally. The facilitator acknowledged and validated her feelings. She then tried to help Vera understand how something like this might happen.

Communicating empathy and understanding was not enough to defuse the situation. Vera needed support to move on from the incident in the garden. Eventually the facilitator offered a diversion to help get Vera's mind off her missing carrots.

Potential Strategies and Supports

It's important to validate an individual's feelings. If that individual has FASD it may be just as important to guide her away from those feelings by starting an alternative conversation around a topic the person feels positive about. When a person with FASD is perseverating it is as if she is stuck in a particular thought pattern. Vera needed support to get "unstuck".

The perseverative topic (stolen carrots) may reappear, and the worker may have to repeat the process to help get her unstuck.

Tamara

Tamara dropped out of school in grade 8. She had two young children, a boy 3 years old and a girl 18 months. She is an attentive mother and likes to make sure her children are clean and well dressed. She likes to style her daughter's hair and seems to have a flair for fashion.

Tamara struggled with addiction to alcohol and was able to go to a treatment program with support from a drug and alcohol counsellor. When she returned to the community she began attending a parenting group. She was excited to be home and quickly formed a relationship with her facilitator. Tamara liked to stay late after group and visit with the facilitator while helping to clean up. The facilitator enjoyed her company and they chatted about all sorts of things.

One day Tamara overheard the facilitator talking on the phone about a course she was taking. The facilitator explained that she was returning to school to complete her degree in social work.
Later Tamara asked her about her plans. The facilitator explained that she had wanted her degree for some time and she finally had an opportunity to return to school.

Later Tamara came to the centre to see the facilitator. She explained that she too had decided to return to school to pursue a career in social work. She wanted to take the same course and attend the same school and asked how and where she should apply.

What's Happening

Tamara is feeling very positive after being in treatment. She is sober, has been eating healthy foods, and feels good about herself and her accomplishment. She also has unrealistic expectations and doesn't realize that she will need to attend school for several years before she can be accepted into a university. In addition, it appears that the facilitator's plans have somehow become Tamara's reality too.

Potential Strategies and Supports

The facilitator and Tamara could look into what it would take for Tamara to return to school. The facilitator could help Tamara visually map out goals, emphasizing Tamara's talent for style and fashion and discussing related career opportunities. What's important is that the facilitator recognizes Tamara may be vulnerable having just returned from treatment. She needs to ensure that Tamara maintains a sense of competence and hopefulness. Tamara will need to be carefully transitioned when the facilitator leaves for school.

Carolyn

Carolyn has been attending a parenting group for the past year. She is pregnant and has two young children. She and the group facilitator have developed a close and trusting relationship. The facilitator has observed that Carolyn has difficulty with language and communication. In addition, she appears easily misled by her peers and has shared that she has difficulty avoiding alcohol on the weekends.

One day Carolyn seemed particularly frantic and asked the facilitator to meet with her. Carolyn seemed to be talking in circles and was having difficulty expressing why she was so disturbed. She mentioned going to a meeting by herself. She met with her social worker and seemed quite distressed and convinced that she was about to lose her children. The facilitator was finding it difficult to determine how she might be able to assist. Finally the facilitator asked in a respectful, calm and supportive manner "What do you need from me?" Carolyn reflected for an extended moment and said, "I need to know what stable means. The social worker said I need to find "stable" housing to keep my kids safe".

The facilitator explained that the social worker expected Carolyn to find an apartment where there was not a lot of partying and where her children could have quiet time. "Oh" Carolyn said, "I just need to find an apartment? I can do that – I already know about a place."

What's Happening

Carolyn is a dedicated mom who knows she will benefit from attending parenting classes and works hard to make sure she attends. She is also resourceful in that she's able to identify supportive people like the facilitator of her class.

Carolyn has difficulty with language and abstract concepts, in this case, the word "stable". She may have been thinking of a stable for horses. She is fearful about losing her children and as her anxiety increases so does her level of confusion and her ability to problem solve.

Potential Strategies and Supports

Carolyn's communication challenges are subtle, and it is important that professionals who work with her are aware of these limitations so they can communicate in a way she understands. Carolyn needs things presented as concretely as possible. She becomes overwhelmed when people talk too quickly so practitioners need to slow down their verbal pace.

Carolyn is trying her best to meet the needs of her children and she needs support and guidance to make good decisions. She may benefit from access to an outreach worker who understands her strengths and limitations or a peer/friend who can offer support. Someone will likely need to accompany Carolyn to appointments and take time to interpret and break down expectations.

Lissy

Lissy is a 24 year old woman who was diagnosed with an FASD as a child. Her parents supported her through high school and she lived at home until she was in her early twenties. Very soon after Lissy left home she became pregnant. Her mom continued to support her as much as possible but her mother said that Lissy seemed to be going through a period of rebellion and her actions were like those of a teenager.

It was late in the month of September and Lissy was due to have her baby on October 5th. Lissy lived with her boyfriend on social assistance. A number of times Lissy's mother mentioned that it might be wise to prepare for the baby's arrival and purchase some necessities for the baby with the money she received each month. Lissy felt she had lots of time and she would respond by saying she would "do that next month". She didn't realize that next month would be upon her in less than 10 days.

Finally her mother showed her a calendar and counted out the days with her. Her mother explained that a due date is only a guess and that sometimes babies come early. She was then able to grasp that if her baby arrived early that meant she would only have one cheque left to get the things she needed. She and her mother made a list together and went shopping that day.

What's Happening

Lissy's developmental age is much younger than her chronological age and so it was not until her early twenties that she experienced the need to distance herself from her parents.

Lissy has difficulty understanding the days and months. Often people who have FASD have difficulty figuring out dates and measuring the passage of time.

Potential Strategies and Supports

Fortunately Lissy had someone in her life who knew what worked with her. Lissy's mother understands FASD and does not expect her to "act her age". When words have no impact, finding a way to make concepts concrete – in this case a calendar - can help people who have FASD to better understand.

Lissy may have been avoiding shopping for the baby because she didn't know what to buy. By working beside her to construct a list, her mother could help Lissy see what needed to be purchased without making her feel incompetent.

Star

Star was a single mom with sole-custody of her infant daughter when she accessed services at an agency for women involved in the sex-trade. In a support group for mothers with addiction issues, she self-identified as having FASD. She also acknowledged drinking during her pregnancy.

Star's baby was apprehended by child welfare authorities and placed for adoption. Losing her child was devastating and Star fell into addiction spiralling into the underground world.

One of Star's relatives stepped forward to adopt her child. The possibility that Star could still be a part of her child's life gave her the strength to get back on her feet. She moved from her home town to another province to be closer to her daughter.

Star has demonstrated amazing courage and persistence. She has overcome her addiction and worked hard so she could be part of her daughter's life. When Star was asked, "What has made the most difference in turning your life around?" she answered, "Having something to believe in and, having someone who believes in me. Nobody in my whole life ever believed in me. Not ever - and then, because people believed in me, I started to believe in myself."

Star hasn't had as much contact with her daughter as she had hoped but she recognizes her need to stay on track in order to maintain visits. Most importantly, her child has been able to remain with family. Star is still doing well and, in spite of her limitations, has managed to maintain a full time job at a local drug store. She saved enough money to buy a car, completed a training program sponsored by her employer, and she has been accepted back to school.

What's Happening

Even though Star is a caring loving mother she could not parent successfully without ongoing one on one support.

Star loves her child and she wants the best for her. This is demonstrated by her determination to overcome her addiction.

She has shown that she has capacity to function well on a daily basis. She continues to benefit from ongoing support and encouragement she receives from her employer.

Potential Strategies and Supports

Star's story is one of courage, faith and hope. Sometimes we need to accept that family can look very different for people and success does not always look the same. In some cases, shared custody and voluntary care, can allow a parent to retain a meaningful role in her child's life.

Having a support network that reaffirms Star's potential and reminds her how important she is to her family and friends helps Star continue to move forward in a positive direction.

Janelle

While in foster care, Janelle was diagnosed with partial FAS. As a young adult, she struggled to care for her three children. During her fourth pregnancy she entered a support program. Janelle had a good relationship with her worker. Her life was relatively stable; she was able to get her children to school each day and had learned enough about shopping and budgeting so that she had food each month.

One week the teachers noticed that Janelle's children were coming to school without lunch. The teachers were concerned and believed this could be the beginning of a child protection issue. A social worker called Janelle to inform her that he would be making a visit. Janelle was fearful her children would be removed and began to feel anxious – she was not sure what she was doing wrong.

Janelle called her support worker. The support worker discovered that Janelle did not have enough money for food that she considered to be "lunch food". She had food in her kitchen, but in her mind, it was not "lunch food" i.e. sandwich food and juice boxes. It had never occurred to her that she could send different food, for example leftover food, to school with her children. The support worker showed Janelle how to prepare lunches from the food she had in the house. She then explained this to the social worker. The social worker felt there was no child protection issue, once she understood the situation. The children once again had lunch and Janelle's anxiety began to subside.

What's Happening

Janelle is working very hard to be a good mom and provide for her children. She has overcome many challenges but her disability makes it difficult for her to generalize information and her thinking can be rigid.

The teachers do not know about Janelle's disability. They have experienced children's lack of food as an indication of serious problems at home. In an effort to protect the welfare of the children the teachers felt that it was necessary to call child welfare authorities.

The social worker was obligated to follow through with an investigation which led to unnecessary stress and anxiety for Janelle.

Potential Strategies and Supports

It would be much better for Janelle if she did not have to experience so much anxiety and distress. Perhaps teachers and the social worker could obtain permission from Janelle to communicate with her support worker, should they have concerns in the future. This way they may be able to problem solve proactively.

Janelle may benefit from parenting classes focused on nutrition along with appropriate supports that will allow her to transfer knowledge from class to home.

Julie

Julie survived an abusive childhood in and out of foster care. She had recently left an abusive relationship and was a single parent of two teenage sons and a two year old daughter.

Julie was eager to learn about the early years and tried to use other services as much as possible. Her young daughter is bright – she is thriving and Julie is a proud parent.

One day Julie and her family had no food. Her worker assisted Julie in acquiring an emergency cheque for $100. The policy for the cheque was such that the recipient must spend all the money – there was no running balance and the store could not provide change. If the recipient spent only $80 the remaining $20 was lost. Nevertheless the full amount is deducted from the recipient's monthly social assistance.

Julie's worker encouraged her to buy food that would carry her family over the week. Julie wanted organic, wholesome food and was attracted to pre-packaged specialty items. Her worker was concerned about Julie's choices because the food was expensive, came in small quantities and would not last the week.

By the end of the shopping trip Julie had only spent $80 and her worker could not convince her to spend the rest. Julie appeared to be tired of the store and she didn't seem to care about the rest of the money.

Her friend lent her $10 for cigarettes and she wanted to buy them in a different store. She'd been out of cigarettes for days and was rolling tobacco from cigarette butts. Smoking is a big part of Julie's social network – she enjoys talking with people in smoking circles and smokes a pack and a half a day when she has money – this would cost her approximately $450 per month.

What's Happening

Julie is a survivor. She cares for her children and is trying her best but she is highly addicted to cigarettes. Although she wants her children to eat well, she is torn by her addiction and sacrifices necessities to buy tobacco. She doesn't seem to understand the effect smoking has on her health.

Julie has difficulty assessing quantity of food and predicting the outcome of her decisions.

Her actions appear irrational but possible reasons could be that Julie is:

- developmentally younger than her chronological age hence she is bored
- overwhelmed from all the stimuli
- fatigued by all the decisions she has to make
- anxious to get out so she can buy cigarettes
- having difficulty understanding the abstract concept of the value of money

Possible Supports and Strategies

Julie may benefit from concrete methods that illustrate the amount of food her family needs. The worker can help move Julie's thinking from organic food to low cost nutritious foods.

At this point the real issue is obtaining enough food for her family. The worker needs to be creative in finding other sources of food. She may be able to respectfully involve Julie in problem solving so she can experience success.

Julie might consider rolling her own cigarettes to economize. If she expresses a desire to cut down or quit smoking, the worker can support her to seriously consider those changes and assist her in developing a plan.

Susan

Susan had just delivered her second child, a baby girl. She had lived through a long history of violent sexual abuse as a child and she was living with an abusive and controlling partner.

Health professionals encouraged Susan to breastfeed her baby and because she had a positive nursing experience with her first child (different father) she naturally proceeded to nurse her second baby.

Susan's partner was not supportive or happy about her decision. In fact, one day she disclosed that her partner called her vulgar names, teased, ridiculed and uttered threats toward her while she nursed her baby.

One day, Susan's worker noticed bruising on her forearm and neck and a burn on her hand. The worker did not press or ask questions. Eventually, Susan disclosed that her partner had beaten her because she was breastfeeding in front of a family member. He accused her of showing off.

Susan moved in with her brother but she still hoped to have the baby's father in her life so she decided it was safer to bottle feed.

Her worker refrained from judging Susan's decision and supported her choice to change to bottle feeding while continuing to promote attachment between mother and child.

Susan felt embarrassed about bottle feeding in front of other professionals and service providers. She understood the expectation that "good" mothers breastfeed and felt she was not able to live up to their expectations. At times she would hide in order to bottle feed her baby. If noticed, she told people that she was not producing enough milk.

What's Happening

Like every mother, Susan wants the best for her children. She wants to keep her baby and herself safe from harm but she also wants to continue her relationship.

Susan's life is extremely complex and the reasons she has for trying to maintain her relationship can vary. It may be that she feels it's important for her child to have her dad in her life or she might be fearful of having to raise her children alone.

At this point she is not able to end her relationship and needs support so she can stay safe and healthy and care for her children.

Potential Strategies and Supports

Susan is vulnerable and she may feel insecure about her decisions and her situation. The worker can provide positive affirmations and remind her that she is a good mother.

When Susan is in a particularly vulnerable situation it's important to avoid overreacting and/or jumping in with solutions. Rather, the worker could check to see if she is hungry and offer her food while maintaining a calm tone and providing a safe environment. At the least this will give her reprieve from a chaotic and stressful situation and she may feel comfortable enough to talk openly at which point the support worker can assist her in exploring solutions.

Talia

Talia had no supports and her partner was vehemently opposed to breastfeeding at the beginning of her pregnancy.

Talia's partner had severe learning disabilities and at one point expressed concern for their baby's intellectual development by saying "I hope he's smart". The group facilitator, support worker and health nurse leveraged opportunities, like his concern, to give him information about the benefits of breastfeeding in terms of brain development.

Eventually, and fortunately before the birth of their child, the father accepted the idea of breastfeeding and supported Talia to nurse.

Talia attended pre and postnatal groups regularly to learn about nutrition and infant developmental needs and learned to nurture and interact with her baby regularly.

These parents are both challenged cognitively and yet their baby thrived because of their genuine desire to provide a healthy environment.

What's Happening

It's important to consider that women's partners may also be survivors of abuse and they can be dealing with many of the same issues as the women we support. The reasons for a partner's opposition to breastfeeding vary and may be due to:

- a degree of immaturity (if the father has FASD his developmental age may be much lower than his chronological age),
- the partner may feel insecure and threatened by the baby especially if service providers are spending a great deal of time with the mom and are focused on empowerment, for the mother, and
- the father may feel jealous toward the baby and his jealousy might manifest in an attempt to limit intimacy between mom and baby.

Potential Strategies and Supports

Support workers are aware of the importance of recognizing and addressing the father's concerns. In addition to actively involving him and providing helpful information, they continue to affirm how important it is for Talia and the baby to have his support. It is important to encourage his involvement in practical ways to help increase his capacity to provide support to both mom and baby.

Jennifer

Jennifer was 21 years old and pregnant with her first child. She attended pre and post natal group and had a good relationship with her facilitator. She delivered a baby girl and when the baby was only three days old she came to the program to show her baby to the staff.

While talking to the facilitator Jennifer shared that she was having difficulty with breastfeeding. Jennifer was under pressure by her peers to feed her baby openly but she felt self conscious feeding her baby in public. In addition she was worried that her baby was not getting enough food. She said she wanted her baby to eat and she couldn't tell how much food she was getting.

The facilitator provided Jennifer with some tips and a cover sheet so that if she was in public no one would be able to see the baby nursing. She also showed Jennifer the "nursing corner" at the program where she could breastfeed her baby in private.

The facilitator then explained to Jennifer that the infant's stomach was very small and she showed her how big the infant's stomach was in a tangible way by comparing the baby's stomach to a walnut. Once Jennifer understood that each time she fed her baby it could take up to an hour because her baby was so young and her stomach was so small she became more comfortable with breastfeeding.

What's Happening

Jennifer's relationship with her facilitator allowed her to be open about her difficulties with breastfeeding. Jennifer may have difficulty with abstract concepts which is why she has benefitted from having concepts around breastfeeding illustrated in a concrete manner. Jennifer is under peer pressure to openly breastfeed. She benefitted from her facilitator's validation that it's okay to cover up while nursing and/or find a place where she can nurse in private.

Potential Strategies and Supports

Jennifer will likely need ongoing support as her infant grows and the demand for food increases. Individuals who have FASD behaviours and characteristics have a tendency to have inflexible patterns once learning has occurred, and it may be difficult for Jennifer to adjust to the length and frequency of feedings to accommodate for growth spurts.

Jacqui

Jacqui was 16 years old. She came to an outreach program when she was about 4 months pregnant. Jacqui had witnessed and survived extremely violent and traumatic events in her short lifetime. Jacqui was very quiet and hardly spoke. She was homeless at the time and roamed from one home to another in order to find a warm place to sleep. Jacqui was always heavily dressed. She wore layers of clothing that covered her entire body including her hands and neck.

Jacqui's outreach worker initiated discussions about breastfeeding early in her pregnancy. Jacqui stated that she did not want to breastfeed her baby. The worker gently suggested that she may want to reconsider. She told Jacqui the health benefits of nursing and at one point said that when breastfed babies catch a cold they generally do not get as sick as babies that are bottle fed. Jacqui held onto the notion that if breastfed her baby would not get as sick as other babies might.

Jacqui gave birth to a 6lb baby boy and decided to nurse him. The worker visited Jacqui every other day. She brought food and offered moral support. Her worker told her how amazing she was for being so open to breastfeeding.

Jacqui was visibly showing more confidence in herself and one day she came to the program dressed casually – her arms and neck were no longer covered. Jacqui nursed her baby for two years.

What's Happening

It's difficult to be sure why Jacqui likes to wear so many clothes. It may be that she is a survivor of sexual abuse or it could have something to do with other trauma that she has witnessed and experienced.

Nevertheless, Jacqui was determined to do the best she could for her baby. She became fixated on the fact that nursing would be good for her baby's health and demonstrated a great deal of strength and determination.

Potential Strategies and Supports

Jacqui's worker offered genuine and practical supports (food). She was sincerely amazed by Jacqui's strength and determination and provided lots of positive feedback. In response Jacqui has done incredibly well – she appears to be very receptive to the worker's support.

Jacqui will need ongoing support to acquire housing for herself and her baby.

It may be helpful to encourage her to participate in a parenting group to further reduce her isolation and increase her capacity to interact with other people.

Kelly

Kelly was 19 years old when she delivered her baby boy. She had been out of the hospital for about a week and the health nurse was concerned about her baby as he was not gaining sufficient weight. Kelly was trying to nurse her son because she had been told it was the best way to feed a baby. She would nurse her son for about a half an hour at a time which she felt was long enough.

The support worker tried to encourage Kelly to nurse the baby longer. She explained the baby's stomach is very small and that it takes a long time to nurse a newborn baby because they can only take in a small amount of milk at a time. The support worker provided a concrete illustration and compared the baby's stomach to a walnut in an effort to show Kelly why it takes more time to feed. Kelly still felt that half an hour was long enough and she became agitated when the baby continued to cry.

What's Happening

Kelly wants the best for her baby and she is trying to nurse however; she may be developmentally younger than her chronological age and have difficulty sitting for long periods of time. She also may have difficulty understanding and telling time, and therefore has no gage to go by.

In addition, breastfeeding doesn't have *concrete* results like bottle feeding. Kelly may have difficulty with *abstract* ideas and because she can't see how much milk the baby has taken in she is unable to understand the infant's need for more food.

Potential Strategies and Supports

Kelly deserves recognition for trying to breastfeed her son. The support worker might be able to reinforce the teaching provided related to signs a baby is feeding well, proper latching, offering both breasts at every feeding, etc.

Some breastfeeding challenges (including weaning and starting formula feeding) may require additional support from a public health nurse or lactation consultant to ensure the health and wellbeing of both mom and baby.

If it is not possible for Kelly to understand that she needs to nurse longer, it may be best to encourage Kelly to bottle feed. This way Kelly will be able to see how much milk the baby drinks at a time.

The important thing is that the baby gets more food and begins to gain weight.

Tammy

One day, Tammy told her group facilitator that she did not want to get pregnant again, at least not right away. The facilitator was concerned because Tammy was sexually active and was not using any birth control. She explained to Tammy that if she continued to have sex without using birth control that she would likely get pregnant again soon. Tammy said, "I don't want to use birth control because it makes you fat."

What's Happening

Tammy cannot connect her actions to outcomes. She knows that she doesn't want to have another baby but she doesn't comprehend the risks associated with being sexually active.

Potential Strategies and Supports

Use different modalities (models, videos, pictures, written words and role plays) to illustrate what happens with sexual activity. Support her in family planning through education. Provide information sessions on the different kinds of contraception, again using pictures and models such as a hands-on learning kit/birth control bin. Provide options in regard to birth control. It will likely be necessary to accompany a woman with FASD to the doctor in order to ensure she gets her needs met as she may have difficulty understanding her options and articulating her choices. For example, a daily birth control pill may not be effective as it is often difficult for people with FASD to organize their daily schedule and remember to take a pill each day. More reliable options include the Depo-Provera shot, an IUD or a tubal ligation.

Erica

Erica was a new mom. One day in group she sat on the couch and snuggled her newborn. She stripped him down to his diaper and held him on her chest while she gently patted his back with her hand. When asked why she removed his sleeper, she replied, "I learned that skin to skin contact was good for bonding with the baby." Erica was fully dressed in a fleece jogging suit. It was cool in the room where the group session took place.

What's Happening

Erica is trying to do the right thing for her baby. She wants to have a healthy bond with her son. She was unaware how cold it was for her baby and she didn't realize that skin to skin contact meant more than her bare hand.

Potential Strategies and Supports

Erica needs specific information about skin to skin contact with her son. The facilitator can explain that she used to lay her baby on her bare chest at bed time and cover the baby and herself up with a blanket so neither one of them got too cold. She might suggest that Erica use a receiving blanket for now so that her baby doesn't feel too cold.

Elise

Elise brought her baby to group. The participants were having a break and she was visiting with her friends. Her baby was clearly overdue for a diaper change. Finally, one of the participants came right out and said, "Hey Mommy – your baby really needs to be changed!" Elise looked perplexed and said, "Oh no, I didn't bring any clothes to change her."

What's Happening

Elise has difficulty with communication and has a tendency to take things literally. She doesn't understand that the term "baby needs to be changed" usually refers to changing the baby's diaper.

Potential Strategies and Supports

The facilitator can quietly explain to Elise that when people say the baby needs to be changed it usually refers to a diaper change. It's important to present this information respectfully in a way that doesn't make Elise feel foolish or stupid.

Elise would likely benefit from individualized, intensive support to ensure she is able to meet the needs of her baby.

Group Facilitation

Facilitating prenatal and parenting groups poses unique challenges when some of the participants may have FASD. This section was developed in consultation with support workers, group facilitators and instructors and offers food for thought, simple tips and suggestions for running effective groups to assist with:

- Recruitment and retention
- Effective group management
- Knowledge transfer from groups to home
- Promotion of self esteem and success
- Support and safety of group participants.

Parenting classes and groups can help to connect parents to other services in the community, reduce isolation and connect parents with each other. During group sessions, participants experience positive social interaction that doesn't involve drugs and alcohol. This is an opportunity to model healthy behaviours and illustrate how people can have fun together and learn without substances.

> *If it wasn't for this class, I would stay home all the time.*
>
> *Group Participant*

Recruitment and Retention

Women who have FASD or other related disabilities may be unable to attend group sessions unless they are provided with support such as reminders, transportation, and assistance with organizational assistance. It's helpful to leverage other community services and/or rework programs to support and complement the group. For example, at times organizations can obtain enhancement funds from government agencies to provide transportation and off site support to women so they can attend.

Create a safe, non- judgmental, welcoming atmosphere. Ensure that women feel welcome by greeting them respectfully and demonstrating genuine interest in their lives. It is important to provide healthy food during each group session. Many women live in poverty with little food and it is difficult to learn on an empty stomach. If possible, arrange a simple cooking activity. Cooking together is fun and it is a concrete learning experience that promotes healthy eating.

Effective Group Management

Ensure the room is set up beforehand and that any audio visual equipment, flip charts, materials and supplies are organized and ready to go. Have a plan and at least one back up plan for group activities. At times, a facilitator may want to try something new, but if the group is clearly not interested it's always good to have an alternate activity.

Write the day's agenda, in simple language, on a whiteboard or a piece of flipchart paper so that everyone knows what to expect. Try to avoid changing facilitators and forewarn participants if there are going to be changes.

Reduce outside distractions and noises as much as possible, lower the stimulation in the room and limit clutter. Some facilitators have found it helpful to hang curtains over cluttered open cupboards. If participants are hypersensitive they could be distracted by the hum of fluorescent lights. If possible, use "no hum lighting".

It's difficult for some people who have FASD to sit still for long periods of time. This is defined as an organic need to move. Provide participants the opportunity to move without disrupting the group. Allow participants to doodle or play with a piece of silly putty.

At times, it can be difficult to bring everyone back together after a break. It may be helpful to round up participants after breaks by physically walking around and gathering them back to group.

Knowledge Transfer from Group to Home

Groups can focus on good nutrition, safety, interpersonal relationships, early child/infant development, play and attachment. Individuals who have FASD may learn concepts in group but be unable to transfer that information to home. Low literacy handouts with step-by-step instructions and picture cues can be helpful. Include a fridge magnet or sticky tack so participants can display the activity easily on a wall or the fridge. If participants are connected to an outreach program with a home visiting component, the worker can assist by running through the exercise or recipe at home alongside the participant.

Build Self Esteem and Encourage Success

Identify participants' strengths and use them as much as possible. In one example, a participant had a gift for remembering where everything was in the kitchen. The facilitator ensured that if the group was looking for something this person was the one they would ask. She would also show new participants around the facility as part of an introduction.

We used to make our crafts ahead of time. Our intention was to provide a concrete example for participants so they would understand what we were hoping to do. Some participants tried to replicate the sample and were so focused on producing a perfect copy that they were not only dissatisfied with the process, they were frustrated and disappointed with their product. Although we had good intentions we were inadvertently setting our participants up for failure.

Now we just bring in all the materials and the instructions and we work through them together. In addition we try to provide activities that are appropriate for a range of ability. Some participants are very gifted in following instructions and others are incredibly creative. Working through it together gives these participants a chance to shine. We talk about how great it is that everyone's project looks different to encourage creativity. Craft activities are now much more satisfying for everyone involved.

CPNP Facilitator

As discussed, individuals who have FASD often have difficulty with abstract ideas. Facilitators can meet their unique learning needs by using a variety of modalities such as videos, pictures and models (for example models of the uterus, fetus, baby food, dolls and diapers).

For participants with a low literacy level, avoid exercises, games and activities that require reading lengthy instructions. If written instructions are a must, rewrite them into simple language and read them together with the class.

Participants can become overwhelmed if sessions are too long –it may be helpful to break topic areas into one hour sessions. When participants want to share stories it's important that the facilitator ensures they do not share stories that could traumatize others in the group. Allow time at the end of the session for participants to talk about their own ideas. This is an excellent opportunity to dispel myths or misunderstandings and encourage participation. This is also a good time to repeat information shared during the session.

Ensure Participants Feel Safe/Supported

Arrange at least two facilitators, especially for groups of 10 or more women. Many women who attend groups are vulnerable, have experienced trauma as children and/or may be involved in abusive relationships. It is crucial that they feel safe in the group. Ensure the discussion is focused on the topic area and keep things light.

Avoid discussions or videos that depict or describe abuse and violence. Women who have similar experiences can be re-traumatized. If someone begins disclosing such events, offer a distraction or if necessary politely stop the conversation and ask to speak to her outside of the room. Check to ensure that everyone is okay before continuing on and in the event that a woman is re-experiencing a traumatic event offer support and if possible connect her to a counsellor.

> *I have found it is absolutely critical to provide an in depth briefing to outside speakers. They need to understand that the women in our group may have FASD and that many have experienced serious trauma. We need to be very careful about the issues we discuss and how we discuss them so that we don't put women at risk of being re-traumatized.*
>
> *CPNP Facilitator*

Other potential tips and strategies:

- Provide a quiet place of retreat for participants should they be overwhelmed either by what's happening in group or what's happening in their lives.
- Be sure to include fun activities to help participants remain engaged. Recall that some participants may have a developmental age much younger than their chronological age.
- Have the group brainstorm the class rules and guidelines together to encourage ownership and cooperation.
- Avoid taking behaviours personally. If a participant shuts down and becomes nonresponsive she can appear disrespectful but it's more likely that she is overwhelmed and needs time to regroup.
- Accentuate each participant's strengths to encourage active participation.
- Avoid didactic lecture and provide exercises that involve participants.
- Understand that, for various reasons, it may be difficult for participants to arrive on time and participate regularly, therefore avoid a punitive approach, for example, "Three no shows and you're out" or "late arrivals not welcome". This is counterproductive and will alienate participants who could benefit from the program.

Some participants face extreme situations at home and have difficulty coping. Having the opportunity to attend a group where they can relax and feel supported may be their life-line.

Support Worker and Facilitator Needs

Often women who have FASD and face multiple challenges are open and hungry for positive feedback and support. This work can be very satisfying and workers feel they are truly making a positive and meaningful difference in the lives of the families they support. This work can also be demanding, confusing and discouraging, especially when women fall into unhealthy patterns. Support workers require ongoing supervision, support and training.

Invariably workers will experience work related trauma when supporting this high risk client group and at times they will be triggered by what they hear or see. It's important to acknowledge that at times they will face adversity and opposition and be in need of formal and informal debriefing with peers and supervisors in order to work through difficult issues. Training and support to maintain healthy boundaries and manage stress can support healthy coping skills and avoid burn out.

> *I was surprised by how much time I had to spend in court with my clients. Sometimes they have to appear for minor offences but because they continually forget or misunderstand they end up in more trouble.*
>
> *Family Support Worker*

Realistic Expectations

Workers need to be aware that each woman has different needs and is at a different place in her life. When we first connect with a woman facing many challenges it's important to empower her to determine her most important issues. For example, a worker may want to address a woman's substance use issues right away especially if she is pregnant but she may not see that as the most important issue especially if she is in need of housing, food or safety. Forcing our own values and beliefs on women will only serve to alienate them – we need to support them where they are. Without first developing a meaningful relationship it is difficult if not impossible to support change.

Awareness of Personal Values and Beliefs

Everyone has a set of values and beliefs about what's healthy, what a family should look like, and what a home should be like. Workers and facilitators need to be open to different beliefs and cultures and accept different norms for their clients.

Self Care

Workers and facilitators can provide guidance and support, but ultimately it is the woman herself who will determine her direction.

> *It's important to know that at times all our best intentions and efforts may not be enough to adequately support an individual toward a healthier life and stable living environment.*
>
> *Family Support Worker*

Workers need to be able to recognize and accept their limitations. In addition, it can be very stressful working with and supporting marginalized individuals who experience extreme trauma, abuse and violence. Chronic stress can have a negative impact on workers' health and wellness; hence, self care is essential.

Self care can include: debriefing with a supervisor or co-worker, accessing professional counselling or coaching, maintaining healthy boundaries, participating in recreational activities, exercise, rest, good nutrition and humour. For each individual, self care may look different - what's important is that workers recognize their own needs and maintain healthy coping mechanisms and strategies to manage stress.

Fetal Alcohol Spectrum Disorder (FASD)

FASD is an umbrella term describing a number of diagnoses including: Alcohol Related Neurodevelopment Disorder; Partial FAS; and Fetal Alcohol Syndrome. FASD can include a variety of physical anomalies, characteristic facial features and brain injury. FASD is caused by prenatal alcohol exposure.

The effects of prenatal alcohol exposure occur on a continuum and range in severity from mild to severe. The degree of severity is influenced by the amount of alcohol consumed, the frequency and timing of alcohol consumption, genetic makeup and the overall health of the mother. Different parts of the body and brain develop at different times during pregnancy. The brain is developing from conception to birth and so it is vulnerable throughout pregnancy. Good nutrition can help to mitigate the effects of alcohol during pregnancy (Thomas, Abou, and Dominguez, 2009 and Keen et al., 2010). Although there are approaches and strategies that can assist people who have FASD to live a fulfilling life, the brain injury that is caused by prenatal alcohol exposure is permanent.

Individuals who have FASD face many challenges, and their need for support varies depending on the severity of brain injury they have incurred. ***It is not known if there is a safe level of alcohol consumption during pregnancy, therefore it is recommended not to drink alcohol during pregnancy*** (Carson et al., 2010).

FASD Behaviours/Characteristics

Following are descriptions of some of the challenges associated with FASD and some of the characteristics/behaviours that are common to individuals who have FASD. These traits have been observed and researched over the last three decades and are described in numerous publications including those by Streisguth (1997), Malbin (2002), and PHAC (2005). Under each description is an example as to how behaviours/characteristics can manifest. These examples are based on observations and were contributed by educators, frontline workers and caregivers.

Impulse control: This behaviour can look irrational, as the individual acts out impulsively, may become angry without warning, or may inappropriately hug, laugh or yell. A typical brain can function somewhat like a filter, allowing people to monitor and control impulses – a person who has FASD may not have that capacity.

> *When an outreach worker saw her client on the street, the client made a vulgar gesture and swore at the worker. As it turned out the client was angered by a recent negative experience - her actions had nothing to do with her outreach worker.*

Abstract Concepts: People who have FASD often take jargon literally and misunderstand abstract concepts involving money, time, responsibility, value, safety and friendship.

> *For example a couple has a "no contact order" and yet they are repeatedly 'caught' together. This couple has difficulty understanding that they have broken the law. They have 'only' talked on the phone, text-messaged, and hung out. They were careful to avoid hugs, and would not sit beside each other so that they did not touch or make 'contact'. Meanwhile, everything they have done is in contradiction with what was agreed upon in court.*

Memory: Short term memory challenges may require the individual to be reminded about the same thing every day. Memory can also be spotty - the individual may remember something day after day and then all of a sudden the information is gone. He or she may be unable to retrieve information she just heard. Impaired working memory affects an individual's ability to consider all the elements of a situation. Once long term memory is activated, this learning may become rigid and difficult to change when new learning is required.

> *A young man had a doctor's appointment and by the time he was sitting in the doctor's office had forgotten why he was there. He tried to make something up because he knew he should have a reason for being there but he couldn't remember it and the doctor was not able to help him.*

Understanding cause and effect: For every personal action there is a reaction that a typical individual can usually predict. Individuals who have FASD, however; have difficulty recognizing the link between their behaviours and outcomes. They do not learn from consequences.

A young woman consistently spends her monthly allowance on restaurant food in the first week of the month even though every time she does that she ends up with no money for the rest of the month. Each month, she does not understand why she has no money left.

Difficulty with Change: It can be very difficult for individuals who have FASD to adjust to changes whether they are environmental or related to rules, times and procedures.

A parenting group had been running on Tuesday mornings for several years. For a number of logistical reasons the group was moved to Thursday mornings. Several participants stopped attending. It was only after the coordinator provided numerous invitations, reminders and offered transportation that they were able to resume their attendance.

Attention/Hyperactivity: An individual who has FASD may struggle to pay attention –she may be easily distracted, become overwhelmed and mentally fatigued within a relatively short period of time. In addition she may have difficulty sitting still.

A participant became irritable and shut down during interactive exercises or games. The facilitator encouraged her to feel free to sit outside the room where it was quiet if things got too loud for her. She was relieved with this option because she wanted to continue coming to group but could not handle the noise level of some exercises.

Chronology: The individual may not have a clear sense of her own history. We carry a chronology of our lives along with us – so we usually have our memories sorted and anchored in the order in which they occurred. We know when key events happened in our lives such as when someone close to us passed away.

One participant's personal timelines appeared to be muddled. She possessed only a vague idea of when certain things happened in her life. Losses from the past occasionally appeared as if they had just happened. For example, her father had passed away close to a decade previously and yet she began to cry uncontrollably about her loss as if it had just happened.

Good Judgment: An individual who has FASD may be unable to make good choices because of an inability to reason out consequences or she may decide without using information from the past.

> *A twenty-five year old woman had three young children between the ages of 2 and 5. She decided she needed a break and agreed to go out for a night with her friends. She knew she could not leave her children alone so she asked her neighbour who was known to be violent to take care of them. Luckily, she had a support worker who intervened beforehand and assisted her in finding someone with whom the children would be safe.*

Difficulty Generalizing Information: An individual may learn a skill or a rule in one place but not be able to transfer that information to another place. Similarly she may be able to complete a task with one set of materials but not another.

> *A child had learned to tie her shoelaces. Her mother was so excited that she ran out and bought her daughter green shoelaces. The girl learned how to tie white shoelaces. She could not tie green shoelaces; she needed to relearn how to tie green shoelaces.*

Organization: The ability to plan daily tasks is compromised for people who have FASD and they may have a reactionary response and difficulty determining the necessary sequence of events to complete a task, and the time each task requires.

> *A young mother was having difficulty with her laundry. She could not figure out what to do first. Her worker suggested they make a step by step list with picture cues to illustrate how to do laundry from start to finish. They posted the list on the inside of her laundry cupboard. One day the worker came to visit and the mom said "I have a pile of t-shirts and I don't know why." When they checked the list and picture cues they noticed they had omitted t-shirts. The mom wrote and drew in t-shirts and was then able to do her laundry.*

Following Through: An individual may be unable to carry information forward and act appropriately even though she appears to understand, and states, what needs to be done. This is a person who can "talk the talk" but has difficulty "walking the talk".

> *A young father can describe the importance and benefits of eating healthily and yet he regularly fills up on junk food and pop.*

Reality: This is often referred to as confabulation. The individual seems to be lying when in fact she is trying to fill in memory gaps and piece together different chunks of information. Something she has seen or was told can become part of her own reality.

> *A young woman had recently watched people skating at the local arena. She did not have a pair of skates, however; during group, later that week she told everyone she had been skating on the weekend.*

Motivation: A person may appear disengaged, tired or lazy when in reality she may be overwhelmed and may not know how to get started. She may be mentally fatigued by the events and in essence "shut down".

> *One client seemed adamant that she wanted to go back to school but she slept in every morning. Her outreach worker offered to set her alarm so she could get up on time. While doing so the worker learned that the client had been setting her alarm for 7:30 pm instead of 7:30 am.*

Social Interaction: Like everyone, people who have FASD want friends, but may be easily misled because of their need to belong. They will take the blame for something if they think it's what a person wants to hear and they are easily manipulated to take blame. They will participate in an activity because they have been asked and give no regard to the level of safety.

> *A father from an outreach program was walking with a group of people. Two people strayed from the group and committed a crime. They returned with stolen goods and told him to "hold this." Then they ran. When the police arrived everyone scattered. With the items in his possession this dad was arrested. He denied everything, but could not explain where the items came from and he did not know the names of the people he was with - only the nicknames.*

Communication Issues: A person who has FASD may not understand what another is saying if that person talks too quickly. Complex language might be unmanageable; also, she may not understand the different applications/meanings of one word or the abstract meaning of idiomatic expressions such as "just grow up," "hit the road," "you need to take responsibility," or "when you are ready."

A young woman appeared to be experiencing labour pains. When her coach inquired by asking, "Are you in pain?" she answered "No". After an hour the coach asked if her stomach hurt and she said emphatically "Oh yes – my stomach really hurts!" When the coach asked "Why didn't you tell me that when I asked if you were in pain?" the woman replied "Pain is something that happens in your head not your stomach."

Cognitive Pace: People who have FASD have been referred to as 10 second people in a two-second world. This can be both embarrassing and intimidating causing the individual to withdraw and seem disengaged. The person may need extra time to answer questions. Silent pauses allow time to process information more efficiently.

One participant told her outreach worker that she doesn't hear every word people say when they are talking to her so she just nods her head and says 'uh-huh, uh-huh.' The outreach worker found that when she slowed down her verbal pace, simplified her language and provided support, this participant could follow through on directions.

Perseveration: People who have FASD may get "stuck" and need support to let things go such as strongly held beliefs, emotions, fascination or something they have heard.

A guest speaker was attempting to begin her presentation but could not get the group's attention because one participant was unable to focus and stop talking. During a short break the participant revealed that she was fascinated by another person's beautiful necklace. When an aide promised to ask this person where she got her necklace the participant was able to pay attention and settle into the group activity.

Sensitivity: Some people can be hyper sensitive while others are hypo sensitive. Sensory issues have a significant impact on an individual's ability to function in a typical fashion.

One client is so sensitive to the sound of the furnace that she cannot concentrate on anything and can become angry, agitated, and disruptive.

Developmentally Younger: Individuals who have FASD are often developmentally younger than their chronological age.

> *A 27 year old woman may have the expressive language of a 27 year old but the social developmental skills of a 10 year old. At times she may present as a mature adult and yet be unable to function appropriately.*

Why do Women Drink Alcohol during Pregnancy?

FASD is an equal opportunity disability (Clarren, 2002). Alcohol use during pregnancy occurs in every racial, ethnic and socio economic group. There are a number of different explanations as to why prenatal alcohol exposure continues to occur.

- Fifty to sixty percent of pregnancies in Canada are unplanned. Most women do not know they are pregnant until at least six weeks gestation and they may unknowingly expose the developing fetus to alcohol.
- Many women are unaware of the risks associated with alcohol consumption during pregnancy.
- There are conflicting messages about the dangers of prenatal alcohol exposure so women may not believe there is a risk.
- Women can be under pressure to drink by family members and peers who disregard the risks associated with alcohol and pregnancy.
- Women may have issues around trauma and post traumatic stress disorder (PTSD) and may use alcohol to numb their pain.
- A woman may have a violent and controlling partner who pressures her to continue drinking.
- Women who are addicted to alcohol may not be able to quit on their own.
- Mothers who struggle with addiction require options for safe, long term child care yet treatment programs that accommodate children are rare.
- Marginalized women who have FASD are at a high risk of delivering children who are prenatally exposed. In addition to FASD related disabilities that inhibit good decision making, these women may have addiction issues.
- There may be cultural pressures to drink alcohol.
- Women may drink to mask or hide a pregnancy, especially if it's against family values to give birth out of wedlock.

In a 2001 study, Nancy Poole and Barbara Isaac discovered through extensive interviews with women who struggled with addiction that the top barriers to treatment were:

- shame
- fear of losing children if they identified a need for treatment
- fear of prejudicial treatment on the basis of their motherhood/pregnancy status
- feelings of depression and low self-esteem
- belief that they could handle the problem without treatment
- lack of information about what treatment was available
- waiting lists for treatment services (Poole and Isaac, 2001).

When women feel shame about their behaviour they may be at greater risk of drinking during pregnancy (Christie, 2011).

No woman purposely sets out to harm her baby. The prevention of FASD is a complex issue that belongs to everyone. Women need education and support in order to have healthy pregnancies.

A Word about Diagnosis

The initial intent for this document was to reflect real life stories about women who are diagnosed with an FASD, but as the search for stories began it became apparent that identifying women at risk who have an FASD diagnosis difficult. Although FASD diagnosis is increasingly accessible, the condition is still, by far, an under- diagnosed disability. It is exceptionally difficult for people over the age of 19 to access assessment and diagnosis.

Adult diagnostic agencies are rare, located only in major centres, and lack funding which means these agencies must charge a significant fee for service. If a person lives outside of a major centre, the organizational and monetary challenges to travel for diagnosis become prohibitive. In addition, adult diagnosis poses a number of unique challenges. In order to provide a proper diagnosis clinicians require school records, childhood pictures and a history of prenatal alcohol exposure, all of which can be difficult if not impossible to obtain later in life, especially if the birth mother has not been involved in the individual's life from an early age.

Frontline workers observe FASD characteristics in many of the women they work with; however, they also report that the condition is not discussed openly. At times there may be a diagnosis in place (especially if the woman was in foster care during childhood) but the woman may not be aware of the diagnosis, or she may not remember being diagnosed, or because of the stigma attached to FASD, she may not want to discuss her diagnosis. Most often workers are not aware of any diagnosis – FASD or otherwise.

These women are often unaware of their own cognitive limitations, possibly because they have developed coping/survival strategies over the years. Although workers are encouraged to be aware of the possibility that clients may have FASD and/or other disabilities, **a *proper FASD diagnosis requires a "trained, interdisciplinary clinical team that uses established criteria"*** (PHAC, 2005).

The issue of an undiagnosed condition like FASD poses an ethical dilemma. If practitioners ignore the possibility that there may be a disability, they may be setting clients/participants up for failure; yet to label a person as having a particular disability such as FASD without a proper diagnosis is unethical.

Workers may need to rely on observations of individual traits in order to make appropriate accommodations to their practice.

A Word about Breastfeeding

Breastfeeding is ideal when it comes to infant feeding and nutrition, however; at times, there may be challenging issues around breast feeding especially if a mom is facing multiple risk factors and has cognitive disabilities.

The following stories illustrate some of the challenges with breastfeeding that have arisen when working with women at risk. When workers were aware of the related issues they were more able to provide appropriate supports so that women could breastfeed successfully.

It's wonderful to promote and support breastfeeding; however it's important to consider each individual woman's capacity and circumstances that may impact her ability to breastfeed. It's possible to put an infant's health at risk if the mom is unable to understand breastfeeding, particularly the time it can take in the early days. A woman's safety may also be in jeopardy should her partner hold strong opposition to breastfeeding.

It is hoped that this document will serve as a valuable teaching tool to support frontline workers and facilitators in their journey with women who live with FASD.

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