



EVALUATION OF FASD PREVENTION AND FASD SUPPORT PROGRAMS

**Philosophy/Theoretical Framework:
FASD Informed**

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FASD-informed

Short Definition

An FASD-informed approach recognizes that Fetal Alcohol Spectrum Disorder is a brain-based disability that has wide ranging effects. An FASD-informed approach also appreciates the diversity that exists amongst people with FASD. Thus, the approach uses knowledge about how FASD may affect a particular person in various and likely multiple areas (i.e., cognitively, emotionally, physically, spiritually, socially, behaviourally, in terms of sensory processing, communication, etc) and also recognizes that for people with FASD, other issues such as trauma may be present. The approach then puts in place adaptations in program design and delivery in order to maximize participants' access to and success within the program.

FASD-informed approach

Definition

An FASD-informed approach uses knowledge about how FASD may affect a person in potentially all areas of life (i.e., cognitively, emotionally, physically, spiritually, socially, behaviourally, in terms of sensory processing, communication, etc.) and also recognizes that for people with FASD, other issues such as trauma may be present; the approach then puts in place adaptations in program design and delivery in order to maximize participants' access to and success within the program.

FASD-informed services recognize that Fetal Alcohol Spectrum Disorder is a brain-based disability that has wide ranging impacts and effects. This means that as a result of the disability, program participants with FASD may have difficulty following certain program rules or behaving in line with practitioners' expectations unless accommodations are made to fit with participants' needs. An FASD-informed approach recognizes that it is the program and/or the practitioners who need to change what they do (i.e., in terms of practice, expectations, program rules, format, etc), rather than the person with FASD, to achieve "a good fit" and positive outcomes (Badry et al, 2015; Dubovsky, 2014; Gelb & Rutman, 2011; Malbin, 2002).

An FASD-informed approach also appreciates the diversity that exists amongst people with FASD – there is a wide range of capabilities, presenting issues, co-existing conditions and issues, and environmental factors that affect people living with FASD; this highlights the importance of tailoring a program or service to the individual as much as is possible.

In addition, an FASD-informed approach recognizes that the majority of those living with FASD, particularly adults, will not have been diagnosed and/or will not disclose

that they may have FASD for a variety of reasons, including the stigmatizing nature of FASD, the adult's memory difficulties and/or lack of appreciation of the relevance of FASD in relation to services (Rutman, 2016).

Community-based service providers, especially those working with people with substance use problems and/or who have experienced violence or trauma, thus need to recognize that a number of their program participants may have FASD (College of New Caledonia, 2013; Grant, Whitney, Huggins & O'Malley, 2009; Rutman, 2016). Along these lines, leading researchers and program providers have noted:

Breaking the Cycle estimates that as many as half of the mothers who are BTC participants are themselves affected by FASD (AWARE, 2011, p.2).

Whether they know it or not, community service providers are often working with people who have FASD. We found this to be the case in our Parent-Child Assistance Program, an intervention for high-risk substance-abusing pregnant/parenting mothers. (Grant, Whitney, Huggins & O'Malley, 2009).

FASD-informed approach: Key Principles and Elements

Drawing on the emerging literature on FASD-informed practice and the more well-developed literature on trauma-informed practice (e.g., Poole & Greaves, 2012; Arthur et al, 2013), principles of an FASD-informed approach have been conceptualized as including (excerpted from Rutman, 2016):

- **Having awareness of FASD** – Recognizing that there is tremendous variability in the capabilities and challenges of those with FASD; equally importantly, the concept of developmental age is more useful than chronological age in providing a sense of a person's functioning (Malbin, 2011). The principle of awareness also includes the idea that FASD-related programs and services need not require service recipients to disclose having FASD or having had an assessment/diagnosis of FASD. Having awareness of FASD also means taking a wholistic approach to programming.
- **Safety and relationship-based** – Central to an FASD-informed approach, the principles of safety and being relationship-based reflect appreciation that the approach begins by developing trusting, positive relationships and creating environments in which the person feels safe to share what is going on in her world. These principles also reflect awareness that many people with FASD may have experienced past, current and/or intergenerational trauma, abuse or violence, and thus integrating FASD-informed and trauma-informed approaches is extremely important (College of New Caledonia, 2013).

- **Being strengths-based** – Highlighting individuals’ strengths and gifts is a key means to counter service systems’ predominant focus on problems and deficits and also counteracts systems’ standard approach of penalizing people for their difficulties. Being strengths-based may involve assisting young people and adults to identify their own strengths and abilities, since doing so may be an unfamiliar experience (Badry et al, 2015; College of New Caledonia, 2013); it may also mean reframing ‘problem’ behaviours as being responses or coping mechanisms to stress, fatigue or trauma.
- **Making person-centred accommodations** – The principle of making person-centred accommodations combines two key concepts: a) being client-centred and thus recognizing individuals’ uniqueness and the heterogeneity that exists amongst people with FASD – i.e., tailoring of service/care plans and program activities based on each person’s life circumstances, social and cultural context; and b) the need to make accommodations or modifications to programming in order to respond to FASD as a brain-based disability.

In addition to these principles, a core facet of an FASD-informed approach is to ensure that there is adequate, up-to-date **training about FASD** for all involved in program planning and delivery, as well as FASD-informed staff supervisions and support and smaller caseloads in recognition of the potential intensity of the work.

Elements of an FASD-informed approach

The following elements of FASD-informed approaches have emerged from literature on promising approaches in working with and providing services to people with FASD (Badry et al, 2015; College of New Caledonia, 2013; Dubovsky, 2014; Rutman, 2011; 2013). the FASD-informed elements have been organized into broad categories: accommodations to practice and communication; accommodations to programming; and accommodations to the physical environment.

Accommodations to service providers’ practice and communication:

- Using Person-first language (e.g., “has FASD”, not “is an FASD child”)
- Using concrete language and examples, minimizing abstract concepts
- Using shorter sentences; building in time to process what is said
- Checking for the participant’s understanding in a respectful and safe way that asks her to demonstrate understanding – not relying solely on the participant’s verbal acknowledgement of understanding
- Using multiple modes of sharing information, and providing simple step-by-step instructions (written and/or with illustrations)
- Making use of physical objects to represent emotions and abstract concepts (e.g. beach ball to represent guilt)
- Providing visual reminders regarding program activities, timing and location
- Providing program participants with reminder calls and/or, if needed, transportation and accompaniment to appointments or program meetings

- Encouraging the participant to bring a support person to meetings to help “translate” information, if needed
- Breaking activities such as goal-setting into small, do-able steps
- Demonstrating and emphasizing self-calming techniques – e.g. breathing
- Demonstrating and practicing role playing and hands-on learning techniques

Accommodations to programming and program format:

- Having routines, structure and predictability in terms of timing and location of activities, and in terms of the service providers involved
- Having flexibility in: program rules in terms of lateness or attendance; allowing participants to move around or fidget during a program activity or meeting; and taking breaks within a session or meeting
- Paying attention to participants’ physical needs such as fatigue or hunger
- Having flexibility in terms of methods of history-taking or other types of information gathering – e.g., use of visual tools such as collage, art, poetry
- Having flexibility and/or adaptations in group programming and process
- Having one-to-one and outreach-based programming, as well as groups
- Recognizing the importance of involving support people (family, mentors, advocate, service providers) in service planning and delivery
- Having (linkages to) supportive housing
- Having family-accessible programs and/or child care resources
- Collaborating with child welfare services to address child protection issues
- Providing transportation, accompaniment and food as program components

Accommodations to the physical environment:

- Photographs of staff on the wall, and/or by the worker’s office door, along with information about the staff member’s role/position
- Reducing noise level and visual clutter, as well as problematic artificial lighting, in order to create calming physical space
- Ensuring that the physical space for meeting has a clearly marked ‘way out’ so that participant does not feel confined. This is especially important for the first meeting, when the relationship is new

Potential indicators of activities and practice, program and community outcomes informed by an FASD Informed approach

As of yet, indicators of FASD-informed service delivery have not been expressly identified within the FASD-related evaluation literature. Thus, as part of the current project, elements of FASD-informed approaches have been reframed as possible indicators of FASD-informed services; potential indicators include:

- **Service providers and managers have training related to FASD** and understand FASD-related characteristics and behaviours

- **Service providers gear their practice to a program participant’s developmental age**, rather than the person’s chronological age, and they interpret a participant’s behaviours in light of understanding of FASD
- **Service providers use “person first” language**; program participant is treated as a person first and as a person who may have FASD secondarily.
- **Service providers employ a relational theoretical framework**, in recognition of the importance of relationships and the need for belonging:
 - Participants feel safe, respected, and not judged or blamed within their relationship with service providers
- **Service providers employ a strengths-based approach**, wherein a participant’s strengths and capabilities are emphasized in the course of service delivery.
- **Service providers make accommodations to their communication** (for examples of accommodations to communication, see preceding section).
- **Service providers make accommodations to their practice** (for examples of accommodations to practice, see preceding section).
- **Service providers make accommodations to the program’s format** (for examples of accommodations to program format, see preceding section).
- **Service providers make accommodations to the physical environment** (for examples of accommodations to the environment, see preceding section).
- **There is an individualized care/plan** for each participant, customized in accordance with participants’ goals, needs, strengths etc; similarly, **one-to-one support** is provided, in keeping with the participant’s individual needs
- Service providers receive ongoing **FASD-focused supervision and mentoring**

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For more tools and resources related to evaluating community-based FASD prevention programs for women including pregnant women and recent mothers, supportive intervention programs for adults and older youth with FASD, and FASD programs in Aboriginal communities, please visit: **www.fasd-evaluation.ca**