
FACILITATORS GUIDE

**Organizing FASD Family/Caregiver
Support Groups**



Introduction

This booklet brings together evidence and experience from key stakeholders in the FASD community and lessons learned from the FASD Support Group Project, a Health Nexus project funded in partnership with the Government of Ontario. The development of this booklet was also funded by the Government of Ontario.

Purpose

This booklet will support parents, volunteers and staff members with:

- Organizing new or enhancing the existing support group activities in your area.
- Evidence-informed considerations that will most likely lead to inclusive and safe group environments.

The evaluation forms at the end of this booklet are being used by groups funded through the FASD Support Group Project and may be copied or adapted as needed for use by other FASD Support Groups.

Acknowledgements

Thank you to the members of the FASD Support Group Project Advisory Committee for their contributions, feedback and support. Thank you to Angela Geddes, MSW, RSW, project coordinator, for her work in writing this booklet.

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Citation

Health Nexus. (2021). *Organizing and Facilitating FASD Family/Caregiver Support Groups: Facilitator Guide*. Toronto, Ontario: Author

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SUPPORT GROUPS

Community-based Fetal Alcohol Spectrum Disorder (FASD) Family/Caregiver Support Groups bring together people who are experiencing the difficulties associated with prenatal exposure to alcohol either themselves, or as a caregiver. Groups are often facilitated by service providers, peer volunteers or ideally both.

FASD Support Groups provide networking opportunities and connections between parents and caregivers affected by FASD. It provides them with an opportunity to come together for culturally-safe mentorship, information sharing and awareness activities.

A support group can be the foundation for life-changing shifts in perspective. An FASD group can support a better understanding of the effects of prenatal exposure to alcohol (PAE) on the individual and the family unit, which often leads to improved circumstances for all (Lutke, 2008). Much of the benefit of support groups comes from the sharing of personal stories with others who are going through similar circumstances, and who understand in ways that others simply can't. People benefit from realizing that they are not alone, and they can learn from the hope, strength, and strategies discussed through personal stories. A support group for many people experiencing FASD provides a safe place where they finally feel understood, and where taboo subjects and uncomfortable stories can be shared.

Support groups have been very well received within the FASD community. Group participants have shared their appreciation for the support they receive and how family members really look forward to 'group day'.

Evidence suggests that a support group has tremendous benefits for the individuals participating.

We know that families do better when:

- They feel less isolated.
- They understand they are not alone.
- They know that their children are understood and supported.
- They can build their own formal and informal support networks.

(Coons, 2014; Health Nexus FASD Support Group Project, 2019)



“I know one time at a parent support group, not so long ago, I had complained about something [my daughter] did and ‘L’ was there, and she said, “G, when are you going to get it? That’s what these people do!” And she understood. Ordinary people don’t understand... So it’s the comfort of knowing people understand.”

– G., adoptive mother of an adult daughter with FASD (Harding & Groom, 2019)

WHAT A SUPPORT GROUP OFFERS INDIVIDUALS AND FAMILIES

The overarching goal of support group activities of all kinds is to leave participants feeling better positioned to handle the difficulties they are facing. A support group should focus on having the participants leave sessions feeling hopeful and inspired. Successful support groups provide a safe space for all where participants can:

1. Feel like they have a place where they belong.
2. Feel understood and accepted.
3. Share their day-to-day challenges and trust that they won't be judged harshly.
4. Celebrate their successes – people need to hear of and learn from strategies and experiences that have led to more positive outcomes.
5. Learn from evidence-informed facilitation and research.
6. Equally give and receive support to and from their peers
7. Relax and enjoy the planned activities.



Facilitators need to be aware that there are some things that can get in the way of these above-mentioned priorities. Skills need to be developed in order to keep the group on track. If not, there is a very real risk that group participants can sometimes leave the group experience with less hope and more fear than when they arrived. Things that can sometimes interfere with a supportive and inspiring experience can be when participants:

1. Engage in conversations that become angry, intense and focused on system gaps.
2. Focus on very serious and critical family issues with a loss of hope expressed.
3. Believe that their lived experience has taught them what others have not yet learned, and then provide unsolicited advice and suggestions that are not in line with current research.
4. Shock other group members with extreme and traumatic stories.

Most FASD support groups rely on volunteers to run as smoothly as they can. Volunteers may be group facilitators, provide administrative or practical support, or offer children's programming. More information about volunteers and volunteer screening can be found on page 5.

THE IMPORTANCE OF FASD-INFORMED FACILITATION

The research indicates that successful support groups do better when co-led by one with lived experience, and one with professional experience linked to a community agency (Mueller, 2019). It is recognized that this is not always possible, but the professional connection can help with providing resources such as space, supplies, administration, and sustainability support. The unique challenges and dynamics mentioned above can be better supported from FASD-informed and skilled facilitators. This allows for one facilitator to be available to help manage additional issues as they arise, i.e. notice if people are struggling and who may need a more private space and a one-to-one approach. It is important to note that there are times when a person is not quite 'group ready', which means that they may be too intensely involved in the grieving process or with their own mental wellness issues which would be better served by individual support or therapy. Many group leaders find it helpful to assess the level of need and whether the group will be a good 'fit' through a pre-group interview with the facilitators. If this is not possible, the facilitator can help its members determine what level of support might be best moving forward. Facilitators need to know where to refer people when needed and to make sure that the group environment remains safe for all. Facilitators need to ensure that members don't 'over-share' and then feel awkward afterwards while other members are left feeling overly concerned about group members and their families. Individuals who are experiencing complex mental health and developmental issues do have special privacy and safety concerns. FASD support groups should ensure that the space is free of judgement and that there are clear group guidelines/rules that have been created/approved by group members. If possible, it would be ideal to have an elder present to support the group process. These guidelines should highlight that confidentiality and participant contributions are highly respected.

NECESSARY CONSIDERATIONS

Here are important aspects of successful group facilitation to consider as you build upon your existing work or you begin brand new support activities within your community:

Confidentiality

1. Address confidentiality from the beginning and with every new member.
2. Ask permission to share last names.
3. Ask members how or if they wish to be acknowledged outside the group and in public spaces.
4. Ask permission before sharing group email lists.
5. Ask permission before taking and sharing pictures.
6. Limit notes to attendance and documenting topics covered. If something serious occurs, use an incident report, in adherence with agency policies.
7. Advise participants of your obligation to report in the event that someone is at risk of harming themselves or others. Police and child protection may need to be contacted as required.



Promoting inclusion and easy access to the group

1. Consider the location of the group. It is helpful to host the group close to public transportation.
2. Assist with transportation if possible. This could include bus tickets, or partnering with volunteer drivers within the community. Ensure accessibility for those with disabilities.
3. Have healthy snack options available as well as treats if so desired.
4. Activities should be inclusive, focused for all parents/caregivers and individuals experiencing FASD.
5. Seek member input to help participants feel like they are a significant part of the group.
6. Prioritize child care if at all possible.
7. Have enough staff/facilitators available to provide safe and enjoyable social and recreational activities. This is a top-level goal of any good support group program.
8. Have members participate in the program planning, development and evaluation.
9. When using virtual meetings consider the following:
 - Your group members have working equipment and access to internet.
 - Use strategies to engage your participants.
 - Keep information and sharing opportunities brief.
 - Use visuals when possible.
 - Include fun activities, like doing a craft, cooking or sharing a meal together.

Volunteer screening

1. Confidentiality applies to all staff, volunteers and participants. Staff and volunteers should sign a form demonstrating their commitment to confidentiality.
2. Police record checks are necessary when working with children and other vulnerable populations.
3. Request support from an agency with clear policies if possible.

Team training and debriefing

1. It is very important for facilitators and/or staff to take a few minutes after every group session to go over the events and dynamics of the group and the participants.
2. This can help avoid facilitator or child-care provider burn out.
3. Debriefing can also help to identify problem areas that can be worked through as a team. For example, if there are communication challenges, or personality difficulties, a team debriefing would allow for these areas to be explored and addressed in a supportive and effective way.

GENERAL STRATEGIES AND TIPS TO HELP THINGS RUN AS SMOOTHLY AS THEY CAN



Safe and welcoming environments need to be created for all, including biological, foster, kinship, and adoptive parents/caregivers. This means that we need to work through some of the anger, guilt, etc., as these emotions are real, natural and not to be judged. These feelings are not overly helpful if they become all-consuming and demonstrated in unhealthy ways. Acceptance and commitment therapy/training and mindfulness are showing some promise to help with these issues. These therapies have been found to help individuals face stressful circumstances of all kinds ‘as they are’ while exploring whether typical coping strategies and responses are working well for all. Support group facilitators and participants need to be trained in an FASD-informed approach in order to understand the unique implications of the disorder. Participation in the support group environment is much easier for all, if members have some key awareness of what the implications of the disorder are, and how best to address them differently.

As most of you already know, it is very important to be flexible: Think of what it is like to have a kitchen table/informal discussion. Have a topic in mind, and resources to share to ensure that participants feel that they have something to take away and learn from their time being spent with the group. That being said, facilitators need to be prepared to change the pace, topic and surroundings at short notice. Let the members of the group ‘own’ the group.

WHAT DO WE DO WHEN?

Someone discloses concerning parenting behavior, and/or if someone is at risk of harm.

1. The duty to report when someone is at risk of harm, is something that needs to be discussed at the beginning of each group, and/or session depending on if there are new members.
2. Participants need to know that this is an obligation, but they also need to feel safe in the group environment. They should be able to trust that others will understand that there is an increased likelihood that relationships are strained, and that parental response does not always represent their core values and intention. It can be very difficult to know how to effectively respond to volatile behavior that may come from a child/youth or adult experiencing FASD, and group members need to feel safe in sharing some of these difficult dynamics.
3. When possible, professional support/facilitation is beneficial to help ensure group safety for all participants. If there is a time when it is necessary to report abuse or serious risk of harm, it is helpful if the family involved is aware and part of the process. This enables relationships and trust to continue through this difficult part of the family's journey.



Someone asks you to do some advocating.

1. Support groups that are a part of the Health Nexus project funded in partnership with the Government of Ontario are funded for family and caregiver support group activities, and not for advocacy, awareness and prevention activities. Participants and leaders are encouraged to gather their informal and formal supports, to do advocacy work outside of the group hours, and not on behalf of the group itself. Support groups not funded by Health Nexus may have different rule about advocacy.
2. Group facilitators are certainly able to be involved in meetings that will help facilitate a deeper understanding of the implications of the disorder that are likely to lead to improved outcomes within the school, child care, social services or recreation environments for examples.
3. Facilitators can provide links and resources to local and provincial advocacy groups which should be listed on the FASD Ontario website. www.fasdinfectsaf.ca/en

How do we handle mixed groups, i.e., kinship, biological, foster and adoptive parents/caregivers?

1. The message that 'we are all in this together' should be well established and discussed in pre-group interviews if you have them and/or at the beginning of groups.
2. There is no benefit to expressing blame and shame, and the message that 'no parent/caregiver intentionally harms their unborn child' should be expressed by group leaders. This is in line with best practices. A supportive message to biological parents is important in terms of having them feel welcome and to engage in the supports which will more likely lead to better child outcomes and reduced prenatal exposures for subsequent pregnancies.

3. Anger and guilt are necessary emotions in order to move things forward in a more positive direction, i.e., system change, and prevention. However, ruminations of any kind are not helpful, and in fact can lead to poor outcomes for all members including those who are ‘stuck’ in their anger and /or guilt. This is something that can be addressed outside of group and as an element of self-care and mental health support for the parents/caregivers. Referrals sources should be well understood by group leaders for all types of additional mental health and grief support.

For more information and further support, we encourage use of the FASD Ontario website found at www.fasdinfectsaf.ca/en, which will enable access to downloadable video and printable resources, as well as a direct link to the agency in your community where the FASD coordinator can be found.

GROUP RULES

The most successful groups ensure that the group members’ voices are heard. It’s important to discuss this ahead of time and do what you can to make sure that the quiet members don’t get overlooked. Many groups have members join in a circle to allow for more personal connection. Many successful groups have some educational components with time also set aside for current issues to be addressed and general question and answer periods. Resources for all topics concerning the special needs of those experiencing FASD can be found on the FASD Ontario website found at www.fasdinfectsaf.ca/en



Sample Rules to get you started:

1. Confidentiality is very important – what is said in the group, stays in the group.
2. There is always a duty to report when someone is at risk of harm.
3. Focus on sharing feelings and experiences rather than advice. People generally do not appreciate hearing unsolicited advice.
4. Share with honesty, but choose how open and transparent you wish to be. Sometimes it’s okay to keep a little to yourself until it is safe to share.
5. Be respectful of the time and the stories of others.
6. Remember that everyone has their own story, and we all only ‘know what we know... We don’t know what we don’t know.’ Do your best to listen carefully, and to reflect before responding or challenging others
7. Be supportive, creative, helpful, and sensitive to others.
8. Share your struggles, but also things that you love and admire about your child/youth/adult who has FASD.
9. Try your best to be on time so not to interrupt the group activities but we do understand that getting out the door with kids can be difficult so please come even if you are running late.
10. Turn off your phones if possible and ‘be’ in these moments.
11. Avoid interrupting or having side conversations.
12. Leave the child care role to the staff and volunteers that are here.
13. Groups supported by the Health Nexus project in partnership with the Government of Ontario are not to participate in Advocacy efforts. It is suggested that individuals consult with local or provincial action groups in this regard.

CONTINUOUS LEARNING: THE IMPORTANCE OF FEEDBACK AND GROUP EVALUATION

There is limited research in terms of actual support and treatment services dedicated specifically for individuals and caregivers experiencing FASD particularly within Ontario. The feedback received from group participants and leaders during the first Health Nexus support group project is contributing significantly. During this first cycle of funding the project received feedback from over 40 group leaders, and over 240 group participants. Below you will find some direct quotes from the evaluation process. This feedback helps us to further understand how meaningful support group activities have been for individuals and families as well as what we can do in order to ensure that they run as smoothly and for as long as they can. This booklet also contains evaluation templates that have been used by the Health Nexus support group projects. These questionnaires have been included as examples and can be used by anyone involved in support group initiatives.

What group participants and leaders are saying:

The first cycle of funding for support groups included standard feedback forms for all group activities. They told us what families appreciate and need and helped us to understand what makes attending support groups difficult. Here are a few quotes to help highlight the benefits that families are experiencing and what makes the support groups work best. The word clouds on the following pages tell us what group leaders see as barriers to support group activities and also what helps to facilitate support for those in need.



“Over time the group has created a family of people who know each other well and help each other out”

“When I go to this group, I am having fun doing lots of different things. I have made friends at the group and sometimes it is hard to make friends and do things with them”

“As a principal of elementary school, this evening is going to impact my decision making and ability to think about symptoms, not behaviors”

“This group has taught me how to love my kids more”

“The group has made me aware that I’m not the only one in the area dealing with this complicated issue”

“Once our local young adults hit a certain age there isn’t many FASD activity’s or supports for them out there that have them connected to other young adults. This group gives them a chance to get out in the community, learn a variety of other things and also connect with similar young adults like them in the community! “

“Many of our attendees would like to see more practical help in the community for their person with FASD. For example, help with housing, employment, life coaching, counselling, etc.”

“It would be good to try to link more caregivers from other areas..... and, perhaps a meeting with all the facilitators and volunteers prior to sessions to make sure they have everything they need for the session”

“Consistently inspire hope; allow opportunities to share experiences and a trained facilitator to support those who are struggling; break group down by age groups... Experiences of those supporting adults with FASD might be overwhelming for caregivers of young children to hear “

Group Participants Feedback

It is important to us that these group activities are meaningful and are helpful for you and your family. We are asking these questions of you to see if participating in these activities is helping to change your experiences, and to learn what we are doing well, and what we can do better. We thank you for your feedback.

All question marked * are mandatory

* Where do you live or work?

* What group are you part of?

* Please tell us about what role you are playing in FASD support group activities.

I am a parent/caregiver of someone experiencing FASD.

I am an extended family member supporting someone experiencing FASD.

I am a child/youth who is experiencing the challenges associated with PAE and/or FASD.

I am an adult who is experiencing the challenges associated with PAE and /or FASD.

* Please rate the following statements by placing an X in the corresponding column

	Strongly agree	Agree	Neither	Disagree	Strongly disagree
I feel safe and welcome.	<input type="radio"/>				
I feel respected and not judged.	<input type="radio"/>				
My ideas are considered for topics and group planning.	<input type="radio"/>				
I look forward to coming to group and continue to attend regularly.	<input type="radio"/>				
I feel more confident in my ability to care for myself, and my family members.	<input type="radio"/>				
I feel that I have learned new skills that make sense and can be used on a day to day basis.	<input type="radio"/>				

FASD Family and Caregiver Support Group Activities Feedback Questionnaire #1

* Please rate the following statements by placing an X in the corresponding column

	Strongly agree	Agree	Neither	Disagree	Strongly disagree
I am finding difficult moments easier to cope with.	<input type="radio"/>				
I am feeling less isolated and alone.	<input type="radio"/>				
I am better aware of FASD specific resources and where to go for help and support.	<input type="radio"/>				

* Please share an example that shows the biggest change this group has made in your life

* Please provide suggestions and ideas on how we can make this support group activity better

Thank you!

Group Staff/Volunteer and Service Provider Feedback

We are asking these questions because it is important for the group staff, service providers and community partners to feel more confident, knowledgeable and supported in order to be most helpful to individuals and families experiencing FASD. We appreciate your feedback.

All question marked * are mandatory

* Where do you live or work?

* What group are you part of?

* Please tell us about what role you are playing in FASD support group activities.

- I am a service provider from a partner agency interested in increasing my skill set in supporting individuals and families with FASD.
- I am a Support group leader who is paid by an agency for my work.
- I am a parent/volunteer support group leader.
- I am a parent/volunteer who is interested in supporting others experiencing FASD.

* Please rate the following statements by placing an X in the corresponding column

	Strongly agree	Agree	Neither	Disagree	Strongly disagree
I have been trained in relevant areas ie. Peer support, mitigating conflict, supporting disclosures, community resources for referral purposes, scope of practice, accountability.	<input type="radio"/>				
I have access to ongoing knowledge exchange, guidance and support.	<input type="radio"/>				
Our support group or activity is flexible in terms of content, criteria for enrolment, and scheduling.	<input type="radio"/>				
People who want to attend can get to group/ events easily.	<input type="radio"/>				
Support activities include a focus on family wellness and self-care for caregivers.	<input type="radio"/>				

FASD Family and Caregiver Support Group Activities Feedback Questionnaire #2

* Please rate the following statements by placing an X in the corresponding column

	Strongly agree	Agree	Neither	Disagree	Strongly disagree
All volunteers and staff use FASD and trauma informed language, practices, and strategies.	<input type="radio"/>				
Our leaders and volunteers take time to debrief, consult and seek guidance when needed.	<input type="radio"/>				
Our group collaborates with other community partners.	<input type="radio"/>				

If so, please indicate how many community partners are involved with your FASD support activities

* Please share an example of why you feel the group is being helpful to you and /or others

* Please share suggestions and ideas as to how we can improve this group and what group facilitators and volunteers need to be the best they can be

Thank you!

Sample Group Staff/Volunteer Confidentiality Agreement

It is very important that people attending this support group activity feel that it is a safe place to share personal information. It is key for all involved (peer leaders, paid facilitators, child care providers and participants) to make a commitment to keeping things shared in group confidential between group members. There are some cases where people do not wish for others to even know that they participate in a support group of any kind, therefore, it is important to check in with people before we openly discuss how we even met for example.

It is a safe and respectful practice to keep any information shared within group activities confidential unless specific permission has been given to share.

It is necessary to break confidentiality only in circumstances where people are at risk of being harmed.

Local Children's Aid Society contact number: _____

Find the phone number of your Children's Aid Society here: www.children.gov.on.ca/htdocs/English/childrensaid/reportingabuse/caslocations.aspx

Kids Help Phone: www.kidshelpphone.ca/

Local police or 911: _____

24 Hour Crises Line contact number: _____

Crisis Services Canada - find your local number at: www.crisisservicescanada.ca/en/looking-for-local-resources-support/

Help Line/Crisis Services: www.oacas.org/what-we-do/communications-and-public-engagement/resources-and-supports-for-ontario-families/#helpline

Health Services Information (ConnexOntario) : +1-866-531-2600 www.connexontario.ca/fr-ca/

Please Note: This is a unique population, and it is more common for people to experience unusual conflict and emotional outbursts that do not often have anything to do with abuse or neglect. Prior to breaking confidentiality, all are encouraged to have a conversation about the sensitive circumstance and inform the individual of any actions you plan to take. Make sure that effort is made to maintain their autonomy and their belief that the group and the system will support them through their difficult part of their journey.

Staff/facilitator name: _____

Signature: _____

Date: _____

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2021