Piruqatigiit Resource Centre

Learning Together Series:

# How to Support Families and Caregivers of People with FASD

#### **GENERAL TIPS**

You may not know of someone specifically, but chances are someone in your circle of friends or acquaintances is affected by Fetal Alcohol Spectrum Disorder (FASD). In Canada, it is estimated that 1 in 25 people (or 4%) have FASD. We can all make our communities more welcoming for families affected by FASD by taking the steps listed below.

#### **BECOME FASD-INFORMED:**

Learn as much as you can about FASD by reading reputable literature and websites or taking workshops through Piruqatigiit Resource Centre. Make sure to listen to the voices of people with lived experience (people with FASD or parents and caregivers). (See attached FASD resources and Piruqatigiit programming).

#### **ADVOCATE:**

Help other people in your networks and circles become FASD informed by sharing information and debunking myths about FASD. When more people understand and practice being welcoming and inclusive, people with FASD and their families will have better quality of life.

#### PROMOTE DIGNITY AND HOPE:

Use person-first language (ie. Person with FASD, person affected by FASD). Stay hopeful and respectful toward families affected by FASD.

See CanFASD's Language Guide for more guidance about respectful language.



# Tips for Being in Relationship with Families Affected by FASD

#### **BE A LISTENER**

Listening and offering empathy can be very helpful. Ask your friend or loved one how you can contribute to their family's needs. Being present as a calm, nonjudgmental support person can be powerful for caregivers.

## LET CAREGIVERS GUIDE YOUR SUPPORT

Try to avoid offering advice or tips unless it is requested. Common parenting strategies and approaches are often not effective for parenting people with FASD. If the caregiver asks for your help, take their lead.

#### DON'T TAKE IT PERSONALLY

Sometimes your friend may seem agitated or irritable or cancel plans, but try not to take it personally. Caregivers of children, youth and adults with FASD experience very high rates of stress. You can help by not adding to the stress when they need to change plans or take a break.

#### PROVIDE SOCIAL CONNECTION

Consistent support such as a text, phone call or tea with caregivers can make a difference. Sometimes the caregiver may not have time or forget to respond; keep contacting them anyway.

#### **OFFER TO HELP WITH CHILDCARE**

If you have a good relationship with a child or youth with FASD and understand their unique needs and strengths, you may consider offering to care for them for short times. This could allow for personal time, stress reduction, and one-to-one time with other children.

Alternatively, caring for siblings of children and youth with FASD can offer much needed rest from some of the difficulties they may experience with the acute needs of their sibling(s).



# ACCOMPANY THEM TO MEETINGS OR APPOINTMENTS

Some caregivers appreciate the support of a friend or family member at school meetings or other appointments involving their child. Being a support person at meetings also helps balance power dynamics if your friend is attending on their own. Taking notes can be helpful so they can focus on the discussion.

### SHARE PEER SUPPORT & LIVED EXPERIENCE

If you are parenting or caring for someone with FASD, reach out to other caregivers. Shared lived experience and peer support can help you to feel less alone and perhaps learn new ways to support a family member with FASD.

# ASSIST WITH ROUTINES AND ACTIVITIES

Offer to support routines and extracurricular activities for a family, if you are able to. If you have children involved in the same programs as a family you are friends with, offer to carpool. This can reduce the amount of transitions for the child with FASD and boost their social connection.

#### **CELEBRATE**

When a caregiver is able to celebrate new growth or something positive, even if it seems small to you, it might be a very important milestone for this family. It means a lot to caregivers when family, friends and loved ones can share in the positive moments and growth.

#### **MODEL RESPECT AND OPENNESS**

If you have children in your life, help them to better understand disabilities, including FASD. Learning about diversity at a young age can help children to be more open and welcoming.

Show children about treating people with respect and looking out for others. If your child has a friend with FASD, also help them to see all of the great qualities of their friend. This helps to create patience, compassion and build empathy.

Look for new children's books coming soon by Piruqatigiit Resource Centre!



#### More Resources

Canada FASD Research Network: www.canfasd.ca

 Caregiver Guide: https://canfasd.ca/wpcontent/uploads/sites/35/2018/03/Caregiver-Resource-Guide-FASD-March<sup>2</sup> 2018.pdf

• Blog: www.canfasdblog.com

**Child First Initiative**: Apply for funding for health and social services for Inuit children www.canada.ca/supporting-inuit-children

Dr. Stuart Shanker Self-Reg & The Mehrit Centre: www.self-reg.ca

POPFASD: Videos and resources www.fasdoutreach.ca

**Kids Brain Health Network:** http://kidsbrainhealth.ca/

**Better Nights Better Days:** Sleep support for children with neurodevelopment disorders http://betternightsbetterdays.ca/

Coming soon: an online FASD training for Nunavummiut! Check piruqatigiit.ca for updates.

#### Contact Piruqatigiit Resource Centre

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