A Discussion on Parenting, FASD, Respite and Mentorship

Parenting is one of the most important things we will do in our lives. It can bring joy, pride, and rewards beyond comprehension. With this, it often comes with challenges that make the rest that much more rewarding. Parenting a child with FASD creates different challenges, bringing out the best, when creating those little (and sometimes big) successes. Some of these difficulties, as described in the literature, include finding time for self-care, dealing with behavior issues, learning problems, sensory issues, social isolation and so forth. It is further noted that respite services, in concurrence with an increased understanding among professionals of the role and expertise that parents of children with FASD have as a result of not only parenting these children, but also their exposure to various different specialized services, needs to be prioritized (Brown & Bednar, 2004).

My experiences at the recent FASD conference, watching parents/care-givers advocate for their children, told me that these individuals are passionate about needing appropriate respite, more mentorship programming (for both youth and adults) as well as assistance in transitioning their children from youth to adult programming. It is well documented that the provision of respite care is a central means of lessening carer stress. Access to high quality, consistent respite has huge benefits with respect to a carer’s ability to fulfill their roles as carers (Mansell & Wilson, 2009). However, it has also been mentioned that the stress of obtaining respite as well as the transition from respite to parent care creates scenarios whereby the benefits of such supports have been questioned. Specifically, the benefits of respite “may be dependent on subjective interpretations and feelings located around placing a child in respite care and dealing with their return” (Hartrey & Wells, 2003). This is only one article, but its emphasis is worth discussion as the purpose of respite is to relieve stress and not create it. (Continued...)
A Discussion on Parenting, Respite (Continued…)

For respite to be effective it is noted that this service needs encompass frequent, high quality breaks that are enjoyable for both the caregiver and their child (Mansell & Wilson, 2009). Understanding what that looks like for all stakeholders (Care-givers, Children, and Respite Services) therefore seems imperative.

That being said, the need for these services do not end when these children become youths. They may be needed more as peer influences, hormones and changes in brain chemistry further complicate an already complex situation. In fact, 88.2% of parents who have youth with intellectual disabilities and psychopathology reported needing help. This was particularly true in the areas of respite, a friendly ear, and mental health information and care (Douma et al., 2006). For this age group, mentorship is key. It is key to these youth developing positive, productive relationships outside the home as well as providing parents with resources and much needed respite.

One mother voiced her concerns at the conference around how her youth had been in a mentorship program for the maximum time allotted, but he was not yet an adult and would not qualify for adult services. In doing so she also expressed her appreciation and subsequent need of this mentorship support. Anticipating the end of this support with no alternative options was greatly distressing, as it would be for any parent whose child is unable to gain appropriate services. These types of gaps are systematic and need to be remedied. (Continued...)

For a list of Respite Services in the Edmonton Area please contact jstrom@bissellcentre.org.
A DISCUSSION ON PARENTING, FASD, RESPITE (Continued…)

Such instances always bring me back to a paper I found when I was just starting out in the FASD world. Anthony Burton, in his article, Anthropology of the Young, states the term “young is intended to apply to all people who exist in cultural situations where they are politically, biologically, or economically dependent on others for reasons that are purely maturational” (1978,55). The simple fact here is that individuals with an FASD are younger than their biological ages. Though profiles of maturity vary, the general ability of FASD individuals to function independently is more realistically placed on a timeline of 25 to 30 years old (Malbin adapted from research findings of Streisguth, Clarren and others, 2008). Understanding and explaining that youth looks different for this population is imperative for a successful transition to adulthood. Realistically, youth services in place to the age of 30 would make more sense. Maybe this is idealistic, as I do not understand the logistics entirely, but it is certainly worth talking more about!

“Young is intended to apply to all people who exist in cultural situations where they are politically, biologically, or economically dependent on others for reasons that are purely maturational”

CITATIONS


"We accord persons dignity by assuming that they are good, that they share the human qualities we ascribe to ourselves." ~ Nelson Mandela
A Few Christmas Time Tips!

- Keep Bedtime as regular as possible
- Keep an eye on sugar intake
- Plan for overstimulation/Have quiet spaces available if possible
- Keep a routine if possible
- Laugh!
- Get lots of fresh air and exercise
- Involve your children in small Christmas tasks (Make a gingerbread house!)

Fetal Alcohol Spectrum Disorder in ALBERTA

Among Alberta women 18 to 44 years of age, 80% reported drinking within the past 12 months.

Given that 40% of pregnancies are reported to be unplanned, a significant number of unborn babies are at a high risk of prenatal exposure to alcohol.

So what can you do? Join the FASD PREVENTION CONVERSATION!

For more information please visit: www.fasdpreventionedmonton.org

Help to spread the messages:

- Alcohol and pregnancy don’t mix. If you drink alcohol and are sexually active, make sure you use effective contraception.
- Friends, partners and family members can support a pregnant woman by asking how they can help her make healthy choices and healthy babies.
- Some women need support, care and treatment to help them stop drinking during pregnancy. Research points to the effectiveness of intervention. Engage them in The Prevention Conversation.

Merry Christmas!