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FASD Awareness Month: Breaking sterotypes and enhancing support for invisible disability

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Local advocates for Fetal Alcohol Syndrome Disorder (FASD) are marking the month of September by raising awareness to help diminish the stigma and improve support for the often-invisible disability.

?The reality is, is that people with fetal alcohol spectrum disorder are often misunderstood,? said Jennifer Moore, chief executive officer of Dufferin Child and Family Services (DCAFs). ?There's a real lack of support for folks in our community as well as their caregivers. It's really important that the public understands the impact of prenatal alcohol exposure on the developing brain.?

International FASD Awareness Day has been recognized annually on Sept. 9 since 1999 and looks to bring global awareness to the disability. Fetal Alcohol Spectrum Disorder, or FASD, is a lifelong disability caused by exposure to alcohol prenatally, which affects the brain and body.

According to the Canada FASD Research Network, fetal alcohol spectrum disorder is the leading developmental disability, with studies suggesting that up to four per cent or 1 in 25 individuals in Canada live with FASD.

FASD can cause difficulty with learning, memory, impulsivity, control and impact academic achievement and social interactions.

?Because it's a spectrum, there's such a wide range of impacts and presentations. It can be challenging because FASD is definitely an invisible disability. People make assumptions about individuals' behaviours, presentations, and interactions without understanding that there may be some type of trauma and brain disability there,? explained Moore.

Part of International FASD Awareness Day is to address the stigma that individuals with FASD and their families face as a result of misinformation surrounding the disability.

A common misconception about FASD is that it is 100 per cent preventable.

The Canada FASD Research Network reports that over 60 per cent of all pregnancies are unplanned.

?One of the big assumptions with FASD is that a mother has been irresponsible during pregnancy and has been drinking alcohol in huge quantities. The reality is, is that's not necessarily the case, and we don't know what levels of alcohol affect what stages of pregnancy,? said Moore.

International FASD Awareness Day also provides families with increased knowledge of available FASD resources in their own communities.

Dufferin resident Joy Blackburn has two adopted children, who are biological siblings, diagnosed with fetal alcohol spectrum disorder.

?We were foster parents, so they came to us as newborn placements and we knew that there had been substance involved, but we didn't have a lot of information. It's never really a shock when you know substances were involved, but our difficulty was getting anybody to listen to us,? said Blackburn.

Speaking with the Free Press, Blackburn said her family's process of getting both her children diagnosed with FASD was difficult,

with an overall lack of knowledge surrounding the disability.

?Because they can present in public like neurotypical kids, people tend to think that we're overstating their difficulties and labeling them. There are doctors and people in general that don't have a lot of education about FASD. There are misdiagnoses and if you don't get the right one, the treatments don't necessarily work the same way,? explained Blackburn.

On FASD Awareness Day (Sept. 9), the Dufferin Wellington Guelph FASD will be hosting a short walk in Guelph to help raise awareness for FASD. The walk will start at 10:30 a.m. in Market Square, located at 62-2 Carden St.

Dufferin Wellington Guelph FASD is also participating in the Annual Red Shoes Rock initiative to help raise awareness.

Red Shoes Rock is a grassroots movement started by Canadian educator and advocate RJ Formanek, who wore red shoes on an international stage to discuss FASD. The movement gained international recognition as a way to bring attention to the disability.

Everyone is encouraged to wear red.

For more information on FASD and support services available locally, visit www.dufferinwellingtonfasd.com.