

## First Peoples Child & Family Review

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### *Journal on Developmental Disabilities* special issue on FASD

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## ***Journal on Developmental Disabilities* special issue on FASD**

The *First Peoples Child & Family Review* was honored to partner with the *Journal on Developmental Disabilities* (JoDD) to produce sister issues on Fetal Alcohol Spectrum Disorder. The following are abstracts from the JoDD's upcoming issue.

### **Meeting expectations**

**Stephen Clifford**

#### *Abstract*

The adoptive father of a young man with FASD tells the story of his family's journey towards getting a diagnosis and how this helped him to better understand his son. He describes the struggles and the joys the family experienced along the way and how the knowledge and understanding that followed the diagnosis enabled them to adjust their expectations in order to improve the quality of life of their son and the whole family.

### **Determinants of drinking during pregnancy and lifespan outcomes for individuals with Fetal Alcohol Spectrum Disorder**

**Kelly Coons**

#### *Abstract*

Fetal Alcohol Spectrum Disorder (FASD) has been identified as a major public health concern. However, limited research has used longitudinal data to track the developmental life course of these individuals. Furthermore, women who drink during pregnancy are not a homogenous group. Concerns regarding drinking behaviours in women who are or could become pregnant are therefore of great concern. The aim of this paper is to provide an overview of a number of risk factors that contribute to a woman's drinking during pregnancy and FASD risk, as well as the subsequent lifespan outcomes that occur in individuals with FASD.

## Media review: *Defendor*

**Bruce Edwards**

### *Abstract*

In this review of the Canadian film *Defendor*, a story of a man with FASD who believes himself to be a superhero, the author turns to interviews with the film's director and star (Woody Harrelson), as well as other media reviews of the film, to explore both the expectations for the film and how it has been received by film critics and movie-goers. The author was a clinician in a diagnostic FASD clinic who met with Harrelson as he prepared for the role. Speaking to Harrelson's efforts to do justice to his portrayal, Edwards concludes that the film delivers a hopeful message about FASD. He notes that the film makes clear the struggles typically experienced by someone with FASD but suggests that it also demonstrates how a person with FASD can make positive difference in the world.

## Why *can't* we be superheroes?: Researchers with and without intellectual and developmental disabilities talk about *Defendor*

**Ann Fudge Schormans, Rebecca Renwick, Denzil Barker, Emanuel Chasi, Bobby Smith, Leslie McWilliam, Sorin Uta, Jory Gruber & Lauren Saks**

### *Abstract*

As part of a research project exploring cinematic representations of people with intellectual and developmental disabilities (IDD), a group of researchers comprised of people with and without IDD reviewed the Canadian film *Defendor*. The group generally liked this film in which the main character, Arthur, is a man with FASD. What was most interesting to us was that the Arthur, like Superman and Batman, was a 'regular guy' during the day but a 'superhero' by night – fighting crime and avenging the death of his mother. The purpose of the research project, however, was to explore how people with IDD are portrayed in Hollywood film and the messages that non-disabled audiences would take from a movie about persons with IDD. It is still rare to see films in which the lead character has an IDD, even rarer to see a person with an IDD portrayed as a superhero. In this review, we talk about whether this portrayal worked to give audiences an alternative way of understanding persons with FASD or reinforced long-standing negative beliefs and attitudes.

## The complexities of caring for individuals with FASD: The perspective of mothers

Debbie Michaud & Valerie Temple

### *Abstract*

Fetal Alcohol Spectrum Disorder (FASD) may be associated with a variety of challenges including developmental disabilities, hyperactivity, attention and impulse control problems, language delays, and social skills deficits. These problems can lead to “secondary disabilities” such as mental health issues, academic and vocational failure, substance abuse, and interactions with the justice system. Parents of children with FASD often struggle with the overwhelming demands of supporting their children. In this study Participatory Action Research was used to address two questions: What are the experiences of parents caring for children with FASD? and What do parents believe their families and children with FASD need to ensure good outcomes? The study included five mothers (either adoptive, foster or biological) of individuals with FASD. In their discussions participants described using unconventional parenting techniques and shared their guilt at being unable to meet the complex needs of their children. They expressed fear for the future as their children moved into adulthood. They discussed the need for lifelong parenting and for smoother transitions between children’s and adult services. Participants felt empowered knowing that they were not alone in their challenges as parents.

## Ontario educators and Fetal Alcohol Spectrum Disorders: A training, resource, and evaluation project

Gal I. Koren, Alexander Sadowski, Talya Scolnik

### *Abstract*

Appropriate school-based support is a critical piece in improving life-outcomes for all children, particularly those affected by Fetal Alcohol Spectrum Disorders (FASD). A 2010 needs assessment highlighted a lack of knowledge about FASD among Toronto public school educators. This paper reports on a new education resource and professional development session on FASD targeting schools around Ontario. Training and resource support was provided to 829 Ontario school staff with varying professional backgrounds and experience during the 2011/12 academic year. The training initiatives were evaluated through participant completion of questionnaires, and descriptive statistics were calculated. Participants were employed across eight school boards which represented enrollment in excess of 575,000 students, or an estimated enrollment of 5,750 (1%) FASD affected children. This initiative was the first learning session on FASD for most participants (75%), and 79% stated that both their own and colleagues’ involvement in this initiative will help future job performance. Ninety-nine percent of respondents reported that the FASD resource serves an important function, may be a useful tool for educators, and that they would recommend it to colleagues. Finally, 93% reported that this initiative led to increased knowledge and confidence in the topic of FASD. This initiative demonstrates that school professionals benefit from resource support and training about FASD, and the Motherisk FASD Clinic module provides a solid, evidence-based, and cost-effective framework for the introduction and continued support on FASD in Ontario schools.

## A mother's plea for her child with FASD

Kathy Moreland Layte

### *Abstract*

This poem, written by an adoptive parent, is a plea for all people to understand the needs and challenges of children born with FASD. It speaks of FASD as an often invisible disability that is not well recognized or supported, and the hardships this can bring for the individual and their family. This lack of understanding and commitment of resources by the broader community can lead to the tragedy of a child with a broken spirit.

## Environmental scan of programs for Fetal Alcohol Spectrum Disorder (FASD) in Eastern Ontario

Danielle Naumann, James Redmond, Holly Smith

### *Abstract*

FASD is a leading cause of developmental disability in Canadian children. The majority of Canadians with FASD are not identified: FASD is diagnosed in less than 1% of Canadians, when it may occur in as high as 2-5% of the school-aged population. This discrepancy is due in part to a lack of harmonized policy and service coordination at national and provincial levels. Failure to provide appropriate interventions for individuals with FASD results in the development of debilitating secondary effects that impact individuals, families and communities. Ontario is the most populated Canadian province with an emerging provincial strategy for FASD that is challenged by additional barriers to effective service provision and utilization. The eastern Ontario region represents a population of 3 million residents that are particularly underserved. This environmental scan used formal and informal sources to explore, summarize, and map out current services for FASD in order to present a comprehensive review of service accessibility. The results inform residents, policy makers, service providers, and program developers on the scope and nature of services for FASD located in the eastern Ontario region in 2012.

## My baby's mother

Elizabeth Russell

### *Abstract*

Written by a foster parent, this poem speaks to the possible thoughts and feelings of a pregnant woman as she looks in the mirror and thinks of her unborn child. Though she loves the child, she still watches herself fill a glass over and over, drinking despite this love. It is a poignant depiction of the conflicting emotions a woman might experience in pregnancy and addiction.

## “A Window of Opportunity”: The proposed inclusion of FASD in the DSM-V

James Sanders

### *Abstract*

FASD is a lifelong disability resulting in clinically significant dysfunction that frequently leads to adverse life outcomes for those affected. Yet, FASD diagnoses are often insufficient to obtain the services and supports that clients need to prevent these secondary disabilities. A Diagnostic and Statistical Manual of Mental Disorders (DSM) diagnosis is widely considered a gateway to treatment and support. Efforts to include FASD in the DSM appear to have begun in the last 10 years. A review of these efforts suggests that reimbursement issues and the enabling of services have been much of the impetus for promoting in the inclusion of FASD in the DSM. Criteria for a FASD-related condition, Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE), have been proposed in section III of the DSM-V as a condition that requires further research. Criteria include the presence of neurocognitive impairment, impairment in self-regulation, deficits in adaptive functioning, and confirmation of more than minimal alcohol exposure any time during gestation. This is a departure from current FASD diagnostic guidelines, which assess growth restriction and facial features in addition to central nervous system dysfunction and prenatal alcohol confirmation.

## “I’m hoping, I’m hoping...”: Thoughts about the future from families of children with autism or FASD in Ontario

Shelley L. Watson, Stephanie A. Hayes, Elisa Radford-Paz, and Kelly D. Coons

### *Abstract*

Applying hope theory, this mixed methods study compared the experiences of families raising children with FASD with families of children with Autism and specifically their thoughts about their children’s futures. Participants filled out two questionnaires, the Parenting Stress Index- Short Form and the Hope Scale. They also participated in in-depth semi-structured interviews. Questionnaire responses revealed that parents of both disability types have several fears for the future, but no significant differences were found between participant groups on the quantitative measures. Although parents of children with both disability types discussed similar concerns for the future in interviews: anxieties regarding level of independence, educational and vocational concerns, and fear of harm, there were qualitative differences in their anxieties. While recognizing that life may be harder, families of children with Autism were hopeful when they spoke about future possibilities; that their children would be fully independent, educated, meaningfully employed, and married with children. In contrast, families of children with FASD recognized their lack of hope for their child’s future, citing difficulties establishing independent living, education, employment, and significant positive relationships with peers and/or partners. Parents of children with FASD also accepted that life might include jail, teen pregnancy, and other adversity. Results are discussed with reference to community awareness and supports available for families of children with Autism and FASD. The importance of mixed methods research is also highlighted.

## Fetal Alcohol Spectrum Disorder: Exploratory investigation of services and interventions for adults

Jessica A. Wheeler, Kara A. Kenney, Valerie Temple

### *Abstract*

The purpose of this literature review was to examine published information regarding interventions for adults with Fetal Alcohol Spectrum Disorder (FASD). The review was limited to articles that included an experimental design (i.e., pre-post measures) to ensure a focus on evidence-based interventions. Due to the limited amount of research available for the adult population, articles included here are primarily interventions aimed at children and adolescents. These were grouped into the following categories: family-centered, cognitive, adaptive training, and community-based interventions. A review of the “Best Practices” document produced by Health Canada (2000) is also presented. Limitations, efficaciousness of practices, and future directions are also addressed with regard to adult services for FASD based on this literature.

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