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# Introduction to Volume 17, Issue 2: General

#### Lynn Martin, Ann Fudge Schormans, and Maire Percy

In this second issue of 2011, 11 original research articles (three research papers, eight brief reports) and two media reviews are featured, representing a variety of topic areas in the field of intellectual and developmental disabilities. Also included is a call for papers for the journal's media review section – we invite researchers, academics, professionals, allies, family members and especially persons with intellectual and developmental disabilities to submit a review.

## **Research Articles**

Karen Auyeung, Julie Burbidge, and Patricia Minnes examine in their article the contributions of child and parent characteristics to stress among parents of children in two age groups – high school and adult. Results from the Family Stress and Coping Interview informed on stressful issues related to caring for a person with ID, and revealed that significant differences existed in the stressful issues reported by parents across age groups and the type of disability. The implications of these findings are discussed, as are directions for future research.

In their original research paper, Anne Ritzema and Ingrid Sladeczek examined the effects of stress in parents of children with developmental disabilities over time using data collected on children attending early intervention (EI) programs over a period of approximately two and a half years. They asked if changes in child behaviour problems and/ or adaptive functioning affected parental stress. At Time 1, child behaviour problems significantly predicted parental stress. Between Time 1 and Time 2, child behaviour problems decreased significantly though there was no significant change in adaptive functioning. At Time 2, child behaviour problems were still found to correlate positively with parent stress, whereas adaptive functioning had a significant negative correlation. The authors discuss the results in the context of current EI practice and policy in Canada.

The support needs of adults with intellectual disability (ID) and pica (the ingestion of inedibles) are the focus of the article by Melody Ashworth and Lynn Martin. They used focus groups to examine the perspectives of staff from institutional and community settings in Ontario on intervention strategies for the reduction of pica. Qualitative data revealed three categories of intervention underpinning reduction in pica and the barriers to implementing these strategies to reduce the impact of pica on the person's life. This study provides V111

#### **Brief Reports**

In their study, Kousha Azimi, Poonam Raina, and Yona Lunsky studied the prevalence of metabolic syndrome among adults with intellectual disabilities treated with atypical antipsychotics in an inpatient psychiatric setting. In their sample of 23 individuals, three quarters were found to be obese or pre-obese, with over one third having been flagged for metabolic syndrome. The authors discuss the need for enhancing metabolic monitoring in this population, as well as the need for alternatives to atypical antipsychotics for treating psychiatric patients with intellectual disability at risk for metabolic syndrome.

Mohamad Abbass and Yona Lunsky studied antipsychotic prescription patterns among adults with developmental disabilities with and without a psychiatric disorder. They found that not many differences existed between those who were and were not prescribed antipsychotic medication, with the exception that those prescribed such medications were more likely to have a mood disorder, higher ratings of non-compliance and hyperactivity, and lower ratings of psychosis. The authors suggest that these findings may indicate that antipsychotics are used for treatment of challenging behaviour, rather than psychosis.

Ami Tint, Suzanne Robinson, and Yona Lunsky examined the experiences of individuals with autism spectrum disorder in the emergency department. They completed a chart review of 24 individuals who had accessed emergency department services for either a psychiatric or medical crisis. They found that the majority of individuals had used the emergency department for psychiatric crises, most of which resulted from episodes of physical or verbal aggression. Issues related to staff training are discussed as a means of improving the experience of persons with autism spectrum disorder in the emergency department. In their study, Jennifer MacMullin, Ami Tint, and Jonathan Weiss examined the relationship between access to professional supports and positive gains experienced by mothers of children with autism spectrum disorder. A total of 132 mothers of children with autism spectrum disorder aged between 4–21 years participated in the study. The findings revealed that professional support was in fact related to positive gains among mothers, controlling for their age and their child's gender, as were behaviour problems. The authors discuss the need for longitudinal studies of positive gain in order to understand how it may change over time.

Maisha Syeda, Jonathan Weiss, and Yona Lunsky used the Brief Family Distress Scale to assess the experience of crisis in a sample of 29 families of individuals with intellectual disability and psychiatric disorder. Their results revealed that more than half of the families in the sample exceeded the cut-off for crisis on the scale; meaning that they were in, or very close to being in crisis. They also reported on the correlation between the score on the Brief Family Distress Scale and related constructs, stressors, and need for services. Ways in which mental health and developmental services can help to improve families' coping abilities and reduce the likelihood of crisis are discussed.

The clinical profiles of 53 persons with dual diagnosis receiving care in community-based specialized treatment beds were examined in a study by Poonam Raina, Yona Lunsky, and Barry Isaacs. Overall, the authors report that autism spectrum disorders and mood disorders were the most common diagnoses, about two thirds were prescribed two or more psychotropic medications; and challenging behaviour - aggression in particular - was exhibited by the majority of individuals. The authors discuss their findings in terms of the ability of community-based specialized treatment beds to meet the complex needs of individuals, as well as the need for more research comparing persons in these specialized beds to those in inpatient settings.

The inappropriate handling of feces is a behaviour that has received little attention in the literature. Jessica Case and Mary Konstantareas used a Functional Behavioural Assessment to attempt to identify factors that influence maladaptive behaviours related to feces in three adults with autism spectrum disorder. They report that factors influencing the behaviours varied for each participant in the study. Furthermore, individualized behaviour modification programs targeting specific variables that maintain the inappropriate behaviours appear to decrease their frequency.

It is known that parents of children with intellectual or developmental disability tend to seek out information and training in order to become knowledgeable about their child's disorder and relevant treatment. However, it is not known if such knowledge influences positive and negative outcomes of parents of children with autism. Using available data on 94 families, Nidhi Luthra and Adrienne Perry have addressed this issue. They report that a moderate positive correlation was found between actual and perceived knowledge. As well, perceived knowledge, but not actual knowledge, was a significant predictor of positive impact but not of negative impact. The study authors also examined how child factors influence parenting stress and positive impact using a statistical approach called hierarchical regression.

### **Media Reviews**

Where's Molly is an autobiographical documentary about Jeff Daly's quest to find his sister, Molly. It chronicles the pair's separation as children and reunion 47 years later. Keri Cameron articulates how this film contributes to our understandings of disability and the effects of institutionalization on families by offering a sibling perspective, a vantage point often absent in media representations of disability and institutionalization. She notes, too, that it has the potential to influence individuals to search for institutionalized family members. Critiquing the documentary through the lens of gender, Cameron argues that the film is however limited in its potential to inform and works instead to reinforce taken-for-granted gender expectations that both fails to consider the multiplicity of forces intersecting at play and resonates with contemporary issues in parenting a child with an intellectual disability.

Lisa Watt reviews The Boy in the Moon, a memoir written by Ian Brown, a Canadian author and journalist, about his quest to find the value of his disabled son's life. Walker Brown was born with a rare genetic condition called cardiofaciocutaneous syndrome (CFC). Watt applauds Brown's generous and honest sharing of his personal struggles and the pain he experiences in caring for Walker, a sharing that Watt asserts validates the experiences of many other parents of disabled children. She identifies Brown's exposure and condemnation of the flaws in what he understands to be a pathetically lean public support system as another strength and important contribution of the book. Yet Watt argues that a major weakness in this book is Brown's failure to challenge the taken-forgranted nature of the conception of "cognitive ability" and its role in determining what does and does not count as valuable human existence. She charges that a failure to do so risks reproducing the discounting and devaluation of people with intellectual disabilities.