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Introduction

Welcome to Issue 15(3) (2009)

This final issue of three with a publication date of 2009 features 10 original research articles (eight research papers, two critical reviews), and two media reports. Following the table of contents, is a list of the reviewers upon whose knowledge and expertise the Journal has drawn for production of issues 15(1), 15(2) and 15(3). Persons who have served as Associate Editors for issue 15(3) are acknowledged along with other JoDD editorial and production staff on the previous page. JoDD is most grateful for the in-kind support of these dedicated people.

Research Articles

Five of the eight research articles in issue 15(3) deal with autism spectrum disorders (ASD). As explained previously, ASDs are also known as pervasive developmental disorders (PDDs). The three most common are a severe form called autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and a mild form, Asperger syndrome. Two rare disorder, Rett syndrome, and childhood disintegrative disorder, also are included. To note is that the term "autism" is often used in two different ways. It is used to refer specifically to autistic disorder and it is also used more generally to refer to all ASDs.

The paper by Stéphane Beaulne explains that autism is now regarded as a [heterogeneous] *neurodevelopmental syndrome* that negatively affects the individual's capabilities for social interaction, communication skills, and range of interests. Beaulne addresses the hypothesis that early neurodevelopmental abnormalities which manifest before a diagnosis of autism is assigned may differ from one child to another, a topic that has received little attention to date. Using results from a semi-structured, parent-based questionnaire, the author defines the neurodevelopmental profile of several autistic children and the age range over which the neurodevelopmental abnormalities first occur. This work has important implications. Determining such profiles may not only help to delineate various subtypes of autism, but also aid with understanding of its causes, and assist with early diagnosis and intervention.

The critical review by Joung-Min Kim and Cheryl Utley addresses the effectiveness of communication interventions for young children with ASD, a topic that has been of increasing interest over the last three decades. In this paper, the authors compiled information from 23 single-subject design studies, published over the time period 1975 to 2007, about

83 young children with ASD who had received "communication intervention." Although "successes" were reported, the majority of studies failed to include documentation about *treatment fidelity* (how accurately or faithfully a program (or intervention) was reproduced from a manual, protocol or model), and about the frequency and intensity of the intervention in their description and implementation procedures. Future research efforts in the field must take heed of these important findings.

A student's Individualized Education Program (IEP) has a direct impact on the development of curricular and instructional services for students receiving special educational services. Parents of students with autism and other disabilities often perceive a disconnect between those services provided by the school and what they perceive that their student needs in order to be successful in life. The paper by Lucy Barnard-Brak and colleagues examines the association of student IEP participation with parental satisfaction among adolescents with autism.

Adaptive behaviours are skills that an individual is able to demonstrate on a day-to-day basis, including self-care skills, domestic and community skills, as well as other skills used in daily life. Adaptive behaviours are often impaired in individuals with autism and intellectual disabilities, but because of the practical utility of these behaviours they are an important area of focus for intervention. However, adaptive behaviours can be challenging to measure. The study by Kerry Wells and colleagues compared three different measures of adaptive behaviour and examined their relationship with severity of autism and cognitive level in a group of individuals with autism and intellectual disabilities. By improving how we measure and understand impairments in adaptive behaviours in individuals with autism and intellectual disabilities we will be better able to design interventions to improve such skills.

Previous research has suggested that stereotypic behaviour may be maintained by sensory consequences produced by engaging in the response. However, few studies have focused on vocal stereotypy. In their pilot study, Marc Lanovaz and Malena Argumedes have compared the effects of differential reinforcement of other behaviour, and noncontingent access to sound-producing toys, on the vocal stereotypy of one child with autism.

As explained by Hélène Ouellette-Kuntz, Shahin Shooshtari and colleagues,

> there is a lack of Canadian studies on the prevalence of intellectual disability and those that do exist have obtained information either through combining the database of departments of social services and education, or identifying affected people in the health services agencies and schools. Both approaches have led to gaps in estimating the number of people with intellectual disability receiving services and supports. To avoid the problem of under determination of milder cases and investigate the prevalence of intellectual disability at the population-level, multiple sources of high quality linkable data from multiple sources for residents of all ages are needed.

The authors have had this opportunity in Manitoba and describe the methodology for estimating prevalence of intellectual disability at the population level using a clear definition and reliable criteria for the term.

Living with a child with cerebral palsy involves tackling a vast range of problems, including dealing with the emotional aspects of having an affected child. Having a sibling with a developmental disability is a risk factor for sibling adjustment problems. Munyane Mophosho, Jacqueline Widdows and Miriam Taylor Gomez conducted a qualitative pilot study which involved interviewing four families' children regarding their perceptions of, and interactions with, their siblings with cerebral palsy. Although the sample size was small, "the most striking emergent themes included acceptance, wishing, helpfulness, responsibility, friendship, and resilience."

In this issue, David Carroll has examined cognitive and emotional language use in narratives of parents of children with Down syndrome versus other developmental disabilities. Unlike Down syndrome, many children with developmental disabilities such as autism and cerebral palsy have uncertain diagnoses and prognoses. The study found that parents of children with other developmental disabilities made more frequent reference to uncertainty, causation, and sadness in their narratives than parents of

children with Down syndrome. These results may help to develop support programs for parents that are specific to their particular needs.

Assertive community treatment (ACT) is internationally a well-established and effective model for providing intensive treatment and psychosocial rehabilitation services to people with severe and persistent mental illnesses. This type of treatment service usually involves an interdisciplinary team of professionals intensively serving a set number of voluntary clients with mental health (e.g., mental health assessment, psychotherapy, crisis supports, medication administration) and social rehabilitation supports (e.g., case management, social and life skills training, home and job finding efforts) in the clients' home environments. Philip Burge carried out a survey of 78 Ontario ACT teams to determine the proportion of their clientele which had intellectual disability (i.e., were dually diagnosed). Considerable unexplained variation in proportions was found when comparing teams and when data were aggregated by teams within provincial health planning authorities. The paper discusses these results and makes recommendations for further study to determine the reasons for this variation.

The critical review by Matthew Wong and Maire Percy provides a multidisciplinary introduction to a genetic neuromuscular disorder called spinal muscular atrophy (SMA) that kills more babies than any other genetic disorder. Because SMA is not associated with cognitive impairment, it is not classified as a developmental disability in Ontario or Canada, although it is in some other jurisdictions. However, lessons learned about SMA have application to other neurological disorders, including fragile X syndrome. Furthermore, since discovery of the genetic basis of SMA in 1996, there have been substantial advances in its understanding and an effective treatment or even cure is envisioned in the near future. Unfortunately, unlike the U.S. and some other countries, Canada does not have an "orphan" drug policy to facilitate the development of promising treatments for rare debilitating disorders. The authors advocate that communities should unite and lobby governments at all levels for policy changes to ensure that all persons affected with rare disorders and developmental disabilities (which collectively affect approximately 1 in 10 in the general population) will have access to life-saving treatments and drugs and a program to cover the costs of such treatments.

Media Reports

"Disability in Dangerous Times" is based on a public lecture given by Catherine Frazee for the Disability Studies Speaker Series, 2009, Ontario Institute for Studies in Education, and New College, University of Toronto, November 5, 2009. As explained in the abstract of this topic,

Dr. Frazee is former chair of the Ontario Human Rights Commission and Professor of Distinction with Ryerson University's School of Disability Studies. In her lecture, given to an audience of disabled academics, activists, advocates and community members, she engages with past and immediate media stories. Dr. Frazee wedges the concerns of developmentally disabled people into these urgent public discussions. In doing so, she exposes the ways in which "public health crises" ignore and sacrifice disabled people. She ends hopefully, urging us to use the stories we hear through the media as an opportunity for empathy.

In her colourful and informative article, Sandra Danilovic introduces the reader to the multi-user, online virtual reality environment of Second Life (n.d.), a free 3-dimensional virtual world where users can socialize, connect and create using free voice and text chat (retrieved February 16, 2010, from http://secondlife.com/?v=1.1). In Sandra's words, Second Life

> provides interesting possibilities for users with disabilities to exist in a parallel virtual universe, a simulacrum of bold colours, phantasmagoric dreamscapes and three-dimensional virtualized replicas of real world locales. 'Autie World' is a cluster of *sims*, or three-dimensional virtual environments that offer promising opportunities of empowerment and support for persons with ASD, as well as advocates, activists, and parents or friends of persons with developmental disabilities.