Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD

Introduction

Welcome to Volume 15, Number 2

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Keywords

action research,
disadvantage and disability,
euthanasia,
film reviews,
longitudinal studies,
methodology,
newspaper articles,
questionnaires, recruitment,
sample size

We are pleased to present eight Articles (two in French), six Brief Reports and two Media Reviews in Volume 15, Number 2 of the *Journal on Developmental Disabilities*. The topics of *autism* and *dual diagnosis* are well represented in this issue and warrant some commentary. Please note that in this Introduction, the terms intellectual disability (ID), developmental disability (DD) and intellectual or developmental disability (IDD) are used interchangeably.

Autism is a common, neurodevelopmental disorder associated with impaired social interaction and communication, and restricted and repetitive behaviours. A neurodevelopmental disorder is one in which the growth and development of the brain or other components of the central nervous system are impaired. Many complicated processes are involved in brain development. These include cell proliferation and growth of brain tissue, cell migration, cell differentiation, myelinogenesis (formation of myelin sheaths around the axons of neurons to facilitate nerve conduction and function), and programmed cell death (apoptosis) which is associated with both development and neurodegenerative disorders. (For a review of brain development in childhood see Johnson, 2008.) Although twin studies have suggested that autism has a strong genetic basis, the origin(s) and cause(s) of autism have remained elusive. Autism is said to be genetically complex because it does not follow predicted patterns of inheritance seen in autosomal, or X-linked dominant and recessive disorders. Autism also is a heterogeneous disorder. This means that different factors or combinations of factors can result in autism. Thus autism will present differently in different individuals depending upon these different combinations of factors. One hypothesis currently under investigation is that certain environmental factors associated with increased risk for autism (including advanced parental age, particular environmental toxins, and vitamin D deficiency) might be mutagenic and contribute to autism by causing de novo mutations (Kinney et al., 2009).

The terms *autism* and *autism spectrum disorder* (ASD) are often used interchangeably, but they do not mean exactly the same thing. Furthermore, the term ASD is sometimes called Pervasive Developmental Disorder (PDD). ASD refers to a broad definition of autism that includes classical autism as well as some closely related disorders that share characteristics with classical autism: (1) Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (a disorder with features that resemble autism but may not be as severe or extensive); (2) Rett syndrome (a genetic disorder affecting girls with neurological signs, including seizures, that become more apparent with age); (3) Asperger syndrome (a disorder with characteristics of autism, but in which language abilities are relatively intact); and (4) Childhood Disintegrative Disorder (a disorder of children in which development appears normal for the first few years, but then regresses with loss of speech and other skills until the characteristics of autism are evident). (For more information about autism and ASD, see Miles et al., 2005; National Institute of Neurological Disorders and Stroke (NINDS), 2009; Perry, Dunlap, & Black, 2007.)

The term *dual diagnosis* also requires some explanation. In many parts of Canada and internationally, this term refers to people who have a mental health disorder and a substance abuse problem. However, in the IDD community in Ontario and several other provinces, dual diagnosis refers to having both lifelong DD and mental health needs. (For more information about dual diagnosis, see the Centre for Addiction and Mental Health Website (CAMH) (2009).)

Articles

The first paper in the series by Denise St. Clair and colleagues at *Westat*, constructs and evaluates factors predicting educational outcome in preschoolers receiving special educational services. Westat is a unique "… employee-owned corporation providing research services to agencies of the U.S. Government, as well as businesses, foundations, and state and local governments" (http://www.westat.com/). Elegant in design and analysis, this study utilized publicly available data from a nationally representative sample of over 3000 young children aged 3 through 5 years who were taking part in the *Pre-Elementary Education Longitudinal (PEELS)* Study.

In a previous research paper, Ann-Louise Davidson demonstrated how *collaborative action research* enabled participants with ID to find out how they understood their ID and what it meant when they said they wanted to talk about it (Davidson, 2009). In the companion paper in this volume, the author vividly describes the interactive action research process by which five adults with ID living in the community examined and evaluated the concept of paid employment and its importance to them.

The concept of emotion regulation in persons with intellectual disability is curiously under-represented in the literature. Kelly McClure and coauthors investigate this topic in their critical review paper. In the first section, the term *emotion regulation* is defined and its importance is explained. Other themes covered in the paper include childhood development of emotion regulation, emotion regulation and psychopathology, emotion regulation studies in populations with intellectual disability, and behavioural regulation of emotion. The paper concludes with a set of specific recommendations for future activities in the arenas of evaluation, treatment, research and communication to ensure that people with intellectual disability are represented in the emotion regulation literature.

Although persons with autism have common deficits, there is much inter-individual variation in their behaviours and level of functioning. As well, autism may be present from birth or develop at a later age. Such clinical heterogeneity complicates research to identify factors that predispose to or cause the disorder. This also interferes with the development of effective treatments or interventions. The highly original review by Stéphane Beaulne summarizes the neurodevelopmental aspects of autism in 4 to 5 year old children. In this paper, he focuses on irregularities of brain structure, abnormalities of psychological development and neurological function, and relationships between these aberrations in such children. He explains the fundamental contribution that neurodevelopmental evidence can make "to our understanding of the heterogeneity in the behavioural manifestations associated with autism." Clinicians and researchers should continue to collect neurodevelopmental information in efforts to delineate homogeneous autism subgroups. The classification of autism into distinct subgroups should not only aid with the development of focused interventions, but also with the identification of its causes, and elucidation of the pathological processes and molecular mechanisms that are involved.

There is ample evidence that children with autism can benefit from certain types of interventions. Intervention services for children and youth with autism are available in some schools. Unfortunately, many children with autism or ASD elude detection until they are of school age. Because making a formal diagnosis of autism is time consuming and costly, and resources to provide services must be used judiciously, there is great need to determine which school children are most in need of services. In order to address this issue, Samantha Goldwater-Adler and colleagues conducted a questionnaire-based study involving 77 primary caregivers of children with ASD and 36 without ASD to see if those with ASD could be distinguished from those without.

People who have recently been released from prison experience many problems. Little is known about their health or what works in improving their health outcomes. Furthermore, among recently released prisoners with ID, challenges are particularly pronounced. The paper by Stuart Kinner and colleagues introduces readers to the plights of ex-prisoners and to a randomized trial of a health-based intervention called *Passport to Advantage* that currently is underway in Queensland, Australia. This study will be "one of the first to explore health outcomes for a large sample of ex-prisoners, some of whom will be found to have ID."

Diabetes is a frequent medical complication in people with ID. Although there are resources for diabetes management intended for persons in the general population, they are not suitable for use by people with ID. The paper by Nicholas Lennox and colleagues describes the development and evaluation of a resource for people with diabetes and intellectual disability and their care providers. This is available in booklet form and as a website for these two target audiences. Development of the diabetes resources should serve as a model for development of other resources to aid people with ID and their caregivers with management of other medical conditions.

Longitudinal studies, in which a group of individuals of similar age are evaluated at regular intervals as they get older, are especially informative in the field of developmental psychology. In particular, these can identify characteristics that are universal or normative (i.e., occur in most members of a group), or which vary among individuals. Despite notable interest, few empirical studies have followed children with developmental disabilities on a longitudinal basis. Furthermore, they have not used multidimensional tools during the symbolic period. Suzie McKinnon and colleagues have taken advantage of the variability in development found among children with ID to explore and evaluate relationships between abilities in seven distinct cognitive domains as a function of time. They conducted a longitudinal study of 25 children with mild to moderate ID and a mean initial age of 50 months over an 18-month period. The changes that they identified in these children demonstrate the importance of assessing children periodically in order to update their developmental profile. Their procedure promotes adjustment of targeted intervention based on the evolving strengths and weaknesses of individuals or in subgroups of individuals. The process they describe should facilitate the selection of intervention goals ranging from the reinforcement of emerging abilities to harmonization of the developmental profile. It also should allow individual and homogeneous small group interventions to be chosen on the basis of multidimensional profiles.

Brief Reports

All of the Brief Reports in this issue correspond to poster presentations on the agenda of the Annual Symposium of the O.A.D.D. Research Special Interest Group Research Day held in Barrie, ON, April 3, 2009.

To determine if different community agencies with dual diagnosis programs are providing the same types of supports and services, Stacy White and colleagues compared characteristics of clients referred to the Dual Diagnosis Program at the CAMH (a specialized clinical program) and the Griffin Community Support network (a crisis support program), which work in partnership.

Among those with a dual diagnosis, clinical profiles may differ by functioning level (mild versus severe intellectual disability). Few studies have examined these differences. In this report, Jonny Elserafi and colleagues examine the relation between clinical profiles in persons diagnosed with dual diagnosis and their level of functioning in a number of patients from the Dual Diagnosis Program at CAMH.

The concept of quality of life and what it means to people with IDD and their families is raising many philosophical and ethical questions. To determine if people with IDD agree with their caregivers about what is important in the lives of adults with IDD, Michelle Viecili and colleagues examined data from preliminary research on the use of the new service application package in Ontario.

A key issue in the dual diagnosis field is how to prioritize supports and services for those seeking help from specialized dual diagnosis programs. To determine if individuals seeking services with a diagnosis of psychotic disorder at the time of referral differed in certain respects from those without, Anna Palucka and colleagues compared:

(i) Individuals who sought services from a dual diagnosis program with and without referral diagnosis of a psychotic disorder

(ii) Hospitalized individuals who had a diagnosis of psychotic disorder on admission and discharge from the inpatient unit with those who had the diagnosis on admission only.

Although children with autism or ASD often can benefit from interventions such as intensive early behavioural intervention, it is not known if dual diagnosis patients with ASD can benefit from specialized, multidisciplinary inpatient treatment. To address this question, Candis Kokoski and Yona Lunsky examined the outcome of inpatient treatment for nine individuals with ASD, in comparison to nine patients with a dual diagnosis without ASD.

Identifying hazards in the environment that might affect the health of children and predispose to, or even cause IDD including autism and ASD, is becoming more and more of concern. To determine if secondary school students are knowledgeable about environmental hazards that might affect the health of fetuses, children and youth and cause or contribute to IDD, Brendan Polley, Kathleen Wheeler, and Maire Percy conducted a series of focus groups with high school students from Grades 10, 11 and 12 at two schools with different demographics. Data generated from the study were compared with published information in the literature or on the Internet.

Media Reviews

The prevalence of autism and ASD is on the rise. Although increased awareness and less stringent criteria for "diagnosis" may be part of the explanation, these factors are not the sole explanations. Research investigating possible causes of autism, knowledge about various types of interventions also is increasing, and advocacy efforts are escalating in this field. The illuminating and entertaining review with the primary title of "Autism Chic" by our Media Editor, Esther Ignagni, deals with the growing prominence of autism in the mainstream media including public service announcements. While being usefully informative, it also raises the troubling issue of how autism is often portrayed by the media as a black and white disorder as opposed to shades of gray, and how "For those whose qualities are not so readily interpreted as "gifts," the new media image of autism may, paradoxically, pave the way for further exclusion."

The review by Jennifer Paterson called *Our Compass* is about an educational documentary film that "profiles the stories of eight youth who attend Compass, a weekly drop in group for lesbian, gay, bisexual, transgender, queer and questioning (LGBTQQ) youth who have been labelled with an intellectual disability." In this review, we are introduced to some of the participants, the challenges they face, the important roles that Compass plays in their lives, and hints about what this film is all about. This film will be publicly released in the spring of 2010.

Acknowledgements

The helpful comments of Suzie McKinnon, Stéphane Beaulne, Ann Fudge Schormans, and Lynn Martin in the preparation of this article are gratefully acknowledged.

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