

Journal on Developmental Disabilities

Le journal sur les handicaps du développement

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Journal on Developmental Disabilities
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Special Issue:

Perspectives on the Autistic Spectrum Disorders

Editors-in-Chief Volume 9 Number 2

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Editorial Policy

The Journal on Developmental Disabilities is published twice yearly by the Ontario Association on Developmental Disabilities (OADD). The Association has established the following objective for the journal:

To foster and promote thoughtful and critical dialogue about relevant issues in the field of developmental disabilities, including those broader social issues that impact on persons with developmental disabilities.

Content

Each issue features a selection of research, conceptual, informational, and editorial papers. An issue may have a central theme. Reviews of relevant books, movies, websites, software, and other resources are welcomed, as are letters to the editor. In this way we strive to collectively enrich our understanding of issues, encourage stimulating debate among those working in the field, and improve services.

Language

Submissions are invited in either French or English and, if accepted, will be printed in the language of submission with an abstract in the other language. Submissions must be free of any gender and ethnic bias. People-first language (e.g., persons with developmental disabilities) must be used throughout the manuscript (including figures and tables).

Editorial Process

Each submission will undergo a peer review by two or more reviewers (typically from the Board of Editors) with relevant expertise. The authors of the manuscripts will not be identified to the reviewers. The reviewers will recommend for or against publication and provide their reasons. Reviewers are asked to judge the manuscript on several criteria including its contribution to increasing our knowledge and clarity of communication. The reviewers are asked to write in a positive and constructive manner to help the authors improve their work, if necessary. All reviews are completed within two weeks using electronic communication.

Final Decision

The Editor-in-Chief, or guest editor, reserves the final decision regarding publication of a submission. To promote the publication of theme issues, the Editor reserves the right to decide in which issue to publish the article if it has been accepted.

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Preface

Rita Eagle and Maire Percy

This special volume of the *Journal on Developmental Disabilities* focusses on autism and autistic spectrum disorders, a group of serious neurodevelopmental disabilities that markedly impair an individual's ability to engage in reciprocal social interaction, to communicate and to participate in age-appropriate activities in an adaptive, functional manner. In recent years, there has been a burst of media attention to these disorders, along with extensive coverage in scientific journals, books, conferences, workshops, and Internet websites, and through organizations and foundations that promote research and education in the field. Through these many sources, we are learning about the great strides that are being made, internationally, towards understanding the biology and etiology of autistic disorders, and towards developing effective means of assessment, diagnosis, early intervention, education and treatment.

Despite these exciting developments, there are still many cracks in our understanding of autistic disorders, and in the delivery of services to assist the individuals with these disorders, and their families. There are also certain issues and challenges that appear to be under-represented in the media, in scientific publications, and in autism conferences and workshops. Amongst these are the plights of individuals whose impairments in communication, cognition and/or behaviour are especially severe, particularly those of older children, adolescents and adults. These individuals may be non-speaking; they may also have, or appear to have, severe or profound cognitive impairment. They may have co-existing psychiatric disorders, and/or present with especially severe behavioural and adaptive difficulties. A review of the literature over the past 20 years finds discussion of these so-called "lower functioning" individuals to be significantly under-represented in research and clinical studies compared to those persons with autism who are described as "higher-functioning" — i.e., those presenting with better communication skills, and normal or near normal cognitive abilities. (See Charmin (1994) and the Ontario Adults with Autism Research and Support Network (2003), for additional detail.)

It is for this reason that, in January, 2001, a conference entitled "Eclipse" was held at Surrey Place Centre in Toronto, Ontario. The purpose of the conference was to bring together people involved in the assessment, provision of services, education and treatment of older children and adults with autism who might be described as more severely affected and/or "lower functioning." "Eclipse" aimed to raise awareness of the complex issues involved in understanding and serving these individuals, to facilitate networking and the formation of advocacy groups, and to generate insight and solutions about what actions might be considered or taken in order to improve the quality of their lives and the lives of their families.

In this special volume of the Journal, we are pleased to publish several of the papers presented at the "Eclipse" conference. The papers cover: assessment techniques for individuals with low functioning autism; mental health issues in individuals with severe autism; non-verbal communicative behaviour; and education, residential placement and treatment approaches for persons who are non-speaking, self-injurious, in crisis and/or suffering from severe trauma. The "Eclipse" papers are joined in this collection by others, written by authors from diverse perspectives, about autism and related disorders. These papers include a review of research in the biology of autism and related disorders. This topic provides new hope in the arena of treatment; it is now clear that "autism" is a heterogeneous collection of disorders that affect the brain for different reasons and that some forms of autism (e.g., that associated with the metabolic disorder of phenylketonuria) actually can be prevented. The biological perspective is represented again in a review of the relationship between autism and the fragile X syndrome. One paper describes a new Ontario initiative in early intervention — the Toronto-based "TPAS" program. Other papers discuss best practices for assessment, diagnosis and treatment, and the sensible, effective use of Internet resources. These are extremely important topics. The need for diagnosis to procure services raises the risk of misdiagnosis. The vast array of interventions and treatment publicized in the media and Internet, which suggest that autism might be substantially helped or even cured, for the most part have not been evaluated in well-designed trials.

The papers in this unique collection represent research findings and the personal experiences of dedicated parents, care providers, clinicians and basic scientists. We are very pleased to present them, and trust that you will find them informative and helpful in your work.

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