

Introduction

Welcome to Volume 15, Number 1

We are pleased to present nine original papers in volume 15, number 1 of the *Journal on Developmental Disabilities*. As in other issues, the papers here illustrate the diversity of methodology that can be used in developmental disabilities.

The paper by Davidson uses action research and involves persons with developmental disability as collaborators to address a real life challenge. Those by Salem et al. and Nguyen et al. demonstrate how studies involving a small number of participants can nevertheless provide information that is very important for the improvement of clinical practice. The papers by Barrera and Garver, Porisky and Minnes, and Carter each feature different procedures for recruiting participants and the use of questionnaires to collect pertinent information. Further introductions to these excellent contributions are provided below.

Articles

The innovative article by Ann-Louise Davidson explains how collaborative action research was used to help five adults with mild or moderate intellectual disability (ID) to understand their ID, to talk about it, and to seek and suggest solutions to challenges associated with being labelled as having ID. Three Social Systems Analysis Tools (Activity Maps, Stakeholder Identification, and Socratic Wheel) were used for this process. Information and communication technologies were highlighted as important advocacy tools. Importantly, the research approach used by Davidson could be applied to foster communication in a diversity of real life situations and to help people with ID to take control of their lives.

Applied behaviour analysis (ABA) is currently recognized as the treatment of choice for children with autism. A common instructional method in ABA programs is called Discrete-Trials Teaching (DTT). Training individuals to conduct DTT normally is a lengthy and expensive process. The pilot study by Sandra Salem and her collaborators has evaluated the training of four university students to administer DTT by means of a self-instructional package, to a research assistant who role-played a child with autism. The results raise the possibility that self-instructional strategies have potential for training of individuals to conduct DTT with children with autism in an efficient and economical fashion.

Functional behaviour assessment (FBA) is a systematic process that enables a caregiver or teacher to describe problematic or challenging behaviour, and to identify the environmental

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factors that cause, sustain or escalate it. FBA also is integral for the development of positive behavioural support plans. Using a checklist they developed for evaluation of challenging behaviours, Francisco Barrera and Erica Graver have compared three functions of challenging behaviour (physical aggression, self-injurious behaviour and property destruction) displayed by a series of 30 adults with developmental disabilities living either in the community (group homes, family residences) or in a large institutional facility. Challenging behaviour functions were found to be similar in both residential settings. Furthermore, the primary function for each type of behaviour was associated with Autism/PDD, the major disorder in the study population, suggesting a biological basis for the findings.

Access to healthcare is important to all Canadians, as it is to people in many other countries, whether or not they have intellectual or developmental disabilities. The paper by Sara Porisky and Patricia Minnes explains how caregiver satisfaction with healthcare access was evaluated for a series of students with intellectual disability living in Eastern Ontario who were preparing to leave high school. Data for this study were collected as part of a larger research project under the auspices of the South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA). Information regarding access to medical care, specialized medical care, and dental care was collected by telephone interview from 63 respondents using three different questionnaires. Although Eastern Ontario is regarded as being “healthcare challenged,” the level of satisfaction about healthcare access in this study was surprisingly high.

Assessing the preferences of individuals with developmental disabilities and arranging the environment to provide their preferred items is one way of implementing the concept of self-determination to enhance quality of life. Preference assessments can be conducted using objects or pictures or both. Concordance between the use of objects and pictures should not be assumed. Duong Minh Nguyen and colleagues hypothesized that teaching object-to-picture matching would improve the concordance between preference assessments using objects and pictures of the same objects.

They addressed this hypothesis in a pilot study involving three persons with developmental disability who had demonstrated high and low preferences using objects but not pictures. In two of the three cases, teaching object to picture matching did improve the concordance, suggesting that mastery of object to picture matching might be a prerequisite for picture preference assessments.

The elegant paper by Irene Carter evaluated the Internet-based self-help group experiences of 22 parental advocates living in the greater Toronto area who have children with autism. Advocates were recruited using three different approaches. An interpretive, qualitative methodology was used to collect information about positive and negative experiences that they had had. Future issues that need to be addressed also were identified.

Media Reviews and Commentaries

The first article in this section is by Ashif Jaffer, who has just completed his first course in the Disability Studies Program at Ryerson University in Toronto. This paper provides a unique perspective about the life of Tracy Latimer and the actions of her father, Robert Latimer. As explained in the introduction to this commentary, Ashif’s perspective is a call “to imagine difference, disadvantage and disability in new ways.”

The second article by Esther Ignagni provides an introduction to and commentary on a documentary entitled *The Freedom Tour*. This was created, directed and video-taped by People First of Canada (2006). It portrays “... the continuing struggle to close institutions for people with intellectual and developmental disabilities across Canada,” and what life has been like for some persons who lived in them. As Ignagni aptly concludes, “*The Freedom Tour* brings us into the places where no one should ever be.”

The final article in this section by Joanne Bacon is a critical commentary about two different pieces of work that describe the agony of having to find alternative placements to community living for loved ones who have a developmental

disability. The first piece reviewed by Bacon is a series of newspaper articles by Ian Brown about his son who lives with cardio-facio-cutaneous syndrome. The second is an award winning film by actress Sandrine Bonnaire about her younger sister who has an undiagnosed/ unspecified autism-like impairment. While acknowledging that both pieces are “seemingly benign,” as well as “powerful, popular, and widely accessible,” Bacon eloquently focuses on perspectives that are not explicit in either work, including the complex issue of whether consent to publish was ever obtained from the individuals whose lives were made so public. She also expounds upon the theme of how both Brown and Bonnaire have equated “difference with defect and tragedy rather than with positive social difference” and how their treatment of the topic “is subtly shaping and reinforcing our negative perceptions of disability.”