

Volume 14, Number 3, 2008

Authors

Maire Percy Ann Fudge Schormans Lynn Martin Ivan Brown

Correspondence

Maire Percy maire.percy@utoronto.ca

Ann Fudge Schormans fschorm@mcmaster.ca

Keywords

Journal on Developmental Disabilities, article types, media reviews, languages

© Ontario Association on Developmental Disabilities

Introduction Welcome to the Journal on Developmental Disabilities and Issue 14(3)

Members of the Chief Editorial Board of the Journal on Developmental Disabilities (JoDD) receive periodic requests about the appropriateness of articles for JoDD. This article describes the different types of material that we consider to be appropriate for publication in JoDD. It also builds on this description to highlight the diversity of the articles included in this issue.

Scope of Articles for Publication in the Journal on Developmental Disabilities (JoDD)

In order to promote knowledge and communication in the field of developmental disabilities, JoDD publishes different types of papers in either English or French from authors all over the world. A potential author can be anyone with an important message, including researchers, students at all levels, service providers, family members, and people with developmental disabilities themselves.

Examples of papers appropriate for inclusion in JoDD include original research articles, critical literature reviews, papers that are conceptual, informational, or editorial in nature, and short reports. An original research article is one that contains new empirical data (such as data produced by experiment or observation) that is presented according to a standard protocol, or one that uses recognized qualitative research methods. A critical literature review is one based upon reading or consulting several or many sources that are specified and that is critical in nature or original in the conclusions that are made. A conceptual paper is one about an issue that cannot be answered simply by getting more factual information. It may also further existing concepts, or offer new concepts or conceptual frameworks. An informational paper educates readers about the status of work in a specific area. An editorial is a paper that states a scholarly opinion of an editor, editorial board, author or authors. Short reports are written in the form of an extended abstract; these typically contain one main figure or table, the introduction and discussion being limited. In JoDD, short reports are often based upon presentations made at an Annual Research Special Interest Group Symposium.

Papers suitable for JoDD also include descriptions of support programs of relevance to the developmental disabilities field, outcome analysis, action research, best practice, and evidencebased program or medicine papers. Outcome analysis is

vi

an approach used in many different fields to determine if a program is worth continuing or not. Action research (or participatory action research) is familiar to those in the education and social sciences, and has, like service-user led and other inclusive and emancipator research strategies, been used more frequently in the field of developmental disabilities relatively recently. This is a reflective, and collaborative approach to problem solving that is useful in real situations. Participatory action research actively accesses the voice and expertise of those most affected by the research issues being explored.

Put simply, action research is "learning by doing" - a group of people identify a problem, do something to resolve it, see how successful their efforts were, and if not satisfied, try again. What separates this type of research from general professional practices, consulting, or daily problemsolving is the emphasis on scientific study, which is to say the researcher studies the problem systematically and ensures the intervention is informed by theoretical considerations. Much of the researcher's time is spent on refining the methodological tools to suit the exigencies of the situation, and on collecting, analyzing, and presenting data on an ongoing, cyclical basis. (O'Brien, 1998; http://www.web.net/~robrien/papers/ arfinal.html#_Toc26184650)

There is no universal definition of what is best practice. The term best practice is often used to describe a program whose success is based upon rigorous evaluation, demonstrates success, has had an impact, and has been replicated. The term replicated implies replication of all specific components of the program under consideration including the methods employed and the nature of the conclusions that can be drawn. The terms evidence based practice or evidence based medicine also do not have a universal definition, but commonly apply to the clinical care of individuals based on the latest science based research in the field.

Letters to the Editor are encouraged by JoDD. A Letter may highlight an issue of concern to JoDD readers, or make a correction to, or respond to, a paper recently published. Narratives from people with disabilities that are written in the first person and speak to the issues being explored in research are welcomed. Other formats used in publications include introductions, forewords and prefaces. An introduction is a beginning section that states the purpose or goals of the articles that follow. A foreword is a piece of writing often found before an introduction that highlights the importance of the content of a publication. It usually is written by someone other than an author or authors. In contrast, a preface is usually written by an author or authors; this may inform readers about what led to the particular content of the publication, and may contain acknowledgements to people assisting with publication. The terms introduction, foreword and preface sometimes are used interchangeably.

research articles and Original program descriptions submitted to JoDD may be pilot in nature or full scale. The term pilot usually refers to a small version of a full scale study as well as the pre-testing of questionnaires or interview schedules. Large studies that are exploratory or descriptive in nature and that do not test an hypothesis (or hypotheses) formulated before the study began on the basis of available evidence also should be considered to be pilot. Pilot studies can be very useful as they provide important insights for future studies. In a full scale study, the sample size and power of statistical analysis should be sufficiently large for the formulation of conclusions at a specified level of confidence, whether they be positive or negative. However, the use of adequate sample size and statistical power does not necessarily mean that the conclusion or conclusions reached will able to be reproduced or generalized. This depends, in part, upon how the research sample was selected, as well as the validity and reliability of the instruments used in generation of the data.

Finally, JoDD will consider the publication of media and resource reviews. As explained in the informative article "Media and the Messages" by Esther Ignagni and Jihan Abbas in the Media Section of this issue JoDD, there now are two types of media: the traditional or "old" (e.g., print, artworks, television and film) and the "new" (e.g., Internet, YouTube, live-streaming, gaming, podcasts, text messages and so forth). JoDD is calling on contributors to take on the challenge of reviewing the media in all of its forms in creative ways! See Ignagni & Abbas, this issue, for additional information.

All material published in JoDD reflects the work and perspectives of the author(s) and not of members of the Chief Editorial Board, or of the Ontario Association on Developmental Disabilities (OADD).

Diversity of Articles in JoDD 14(3)

This issue includes five original research papers (of which two are in French with English abstracts provided), one commentary, one critical literature review, and two program descriptions. In recognition of the ubiquitous presence of media in our lives and its influence in constructing and shaping how we think about disability, each issue of the JoDD will now include a media review section. In this issue, this section consists of an introductory article and three reviews.

Research Papers

- In their full scale paper involving information collection by means of standardized questionnaires and the application of multivariate statistical analysis, Jonathan Weiss and James Bebko (York University and the Centre for Addiction in Mental Health) identify factors resulting in improvement in self-concept in 49 persons with developmental disabilities who took part in traditional Special Olympics over a period of 42 months.
- In an analysis of 36 books using a linguistic procedure called quantitative text analysis, David Carroll (University of Wisconsin-Superior) examines how parents of children with developmental disabilities and parents of typically developing children construct narratives about their children. Some surprising differences are revealed in this highly original study.
- Using specially designed questionnaires completed by approximately 100 parents, Annie Poirier and Georgette Goupil (Hôpital Rivière-des-Prairie and Université du Québec à Montréal) evaluate processes involved in the diagnosis of pervasive developmental disabilities (PDD), including autism, Asperger's syndrome and pervasive developmental disorders otherwise

unspecified (PDD-NOS), in Quebec. The first paper addresses the steps involved in obtaining official diagnoses. The second one deals with parents' perception of the professionals who communicated the diagnosis and information provided about the diagnosis. The take-home messages from these studies should be heeded by other groups involved in similar activities.

 Using novel test procedures developed for assessment in their laboratory, Laura Jackson and Cristina Atance (University of Ottawa) examine future thinking ability in a pioneering study of 12 children with autism spectrum disorders.

Commentary

 The paper by Andrea Betts (York University) explains the concept of professionalism, and makes a case for classification of service providers who work in group homes, in particular, as professionals.

Literature Review

• The article by Shelley Watson (Laurentian University) examines the pros and cons of obtaining a "differential diagnosis" for people with developmental disabilities. (The term "differential diagnosis" includes the assignment of diagnoses such as Down syndrome or fragile X syndrome as opposed to general classifications such as pervasive developmental disorder, or general global delay.)

Program Descriptions

- Fanny Silber (Israel) describes a classical music therapy program that she developed especially for persons with severe cerebral palsy in a day care centre in Israel to help them to understand the concept of "farewell" – how they might feel when they have to leave the school at age 21. Anecdotal comments made by students in the program are included.
- Raymond Leblanc (University of Ottawa) and collaborators describe an innovative cooperative housing program for adults

with developmental disabilities that was implemented in a university residence with the assistance of a group of graduate students taking a course for credit. The paper demonstrates how action research – collaboration between the "insiders" (the adults with developmental disabilities) and the "outsiders" (the authors of the paper) – was used to enhance the quality of this program.

Media Reviews

- The Media Reviews section of JoDD begins with an introduction to the importance of the media in the developmental disabilities field by Esther Ignagni and Jihan Abbas (Ryerson University). Ignagni and Abbas also invite and challenge future contributors to take up the multiplicity of messages and forms of media and the questions posed by both "old" and "new" media to our understandings of developmental disability. This piece sets the scene for three reviews arranged by Ignagni.
- "Out From Under", provides commentary about the "Out From Under: Disability, History and Things to Remember" exhibit at the Royal Ontario Museum that was curated by Katherine Church, Catherine Frazee, and Melanie Panitch from Ryerson's Disability Studies Program. This review was done by the "Compass" group (a group from the Griffin Centre for young people with developmental disabilities to explore sexual and gender identities, including youth who identify as lesbian, gay, bisexual, transgender, transsexual, intersex, two-spirit, queer and questionning) in collaboration with Jennifer Paterson (Ryerson University) and Tess Vo (Griffin Centre).
- In "Autism: The Musical", Morgan Ineson (Canadian National Institute for the Blind) reviews the documentary film of the same name.
- The Media section ends with a review by Pamela Cushing (University of Western Ontario) of two websites – www.powertobe. ca and www.disaboom.com.

Bibliography

- Altman, D., Burton, N., Cuthill, I., Festing, M., Hutton, J., & Playle, L. On behalf of the NC3Rs Experimental Design Working Group. (n.d.). Why do a pilot study? National Centre for the Replacement, Refinement and Reduction of Animals in Research. Retrieved October 4, 2008, from http://www.nc3rs.org.uk/downloaddoc.asp?id=400
- Chief Editorial Board, Journal on Developmental Disabilities. (2007). Revisiting the concepts of reliability and validity. *Journal on Developmental Disabilities*, 13(3), vii-xiii.
- Gocsik, K. (2004). What is an academic paper? Dartmouth Writing Program. Retrieved October 6, 2008, from www.dartmouth.edu/~writing/ materials/student/ac_paper/what.shtml
- Handouts and links. Literature reviews. (2007). The University Center, University of North Carolina at Chapel Hill. Retrieved October 6, 2008, from www. unc.edu/depts/wcweb/handouts/literature_review.html 34k Cach
- How to write a book review. (2005). Los Angeles College Library. Retrieved October 28, 2008, from http://www.lavc.edu/Library/bookreview.htm
- Isaacs, D., & Fitzgerald, D. (1999), Seven alternatives to evidence based medicine. British Medical Journal, 319(7225), 1618. Retrieved November 8, 2008, from http://www.bmj.com/cgi/ reprint/319/7225/1618.pdf
- Lancaster, G. A., Dodd, S., & Williamson, P.R (2004). Design and analysis of pilot studies: Recommendations for good practice. *Journal of Evaluation in Clinical Practice*, 10(2), 307-12
- O'Brien (1998). An overview of the methodological approach of action research. Faculty of Information Studies, University of Toronto. Retrieved November 1, 2008, from http://www.web.net/~robrien/papers/arfinal.html#_Toc26184651
- Preventing chronic disease. Public health research, practice, policy. Centers for Disease Control and Prevention. Reviewer checklist for original research. (n.d.). Retrieved October 6, 2008, from www.cdc.gov/pcd/for_reviewers/checklists/original_research.pdf -
- Public Safety Canada. NCPS. (n.d.). Conducting economic analysis. Section 2.1. A model for process and outcome analysis. Retrieved November 1, 2008, from http://ww4.ps-sp.gc.ca/en/library/publications/reports/manual/manual_2.html
- Ruxton, G. D., & Colegrave, N. (2006). Experimental design for the life sciences (2nd ed.). Oxford: Oxford University Press.
- Sacket, D. L., Rosenberg, W. M. C., Gray, J. A. M., Haynes, R. B., & Richardson, W. S. (1996). Evidence-based medicine: What it is and what it isn't. *British Medical Journal*, 312, 71-72.

- Sample, P.L. (1996). Beginnings: Participatory action research and adults with developmental disabilities. *Disability and Society*, 11(3), 317-332.
- Ward, K., & Trigler, J.S. (2001). Reflections on participatory action research with people who have developmental disabilities. *Journal on Mental Retardation*, 39(1), 57-59.
- What is original research. UNF Library Student Guide. (n.d.). Retrieved October 5, 2008, from http://www.unf.edu/library/guides/originalresearch.html
- van Teijlingen, E. R., & Hundley, V. (2001, Winter). The importance of pilot studies. Department of Sociology, University of Surrey, Guilford, UK: Social Research Update. Retrieved October 4, 2008, from http://sru.soc.surrey.ac.uk/SRU35.html
- Weiss, J., & Perry, A. (2007). Evidence based practice in developmental disabilities: What is it and why does it matter. *Journal on Developmental Disabilities*, 13(1), 167-171.