

## **Foreword**

### **Revisiting the Concepts of Reliability and Validity**

Many research projects include, or are wholly based upon, data collected by some form of survey or questionnaire. In some cases, the instrument used for data collection exists, but in other cases it does not. In the latter case, an investigator is faced with the task of designing this tool. Although development of a new instrument for data collection may seem like a daunting task, this need not be the case. A tremendous amount of expertise already exists within our field. Chances are that if a prospective researcher has questions or concerns about how to develop an instrument for data collection, or indeed about the overall design or data analysis plan of a research study involving application of the instrument, others already have encountered such issues and have developed strategies for addressing them. As well, many universities and agencies have research support units that can help investigators develop sound plans for experimental design and analysis.

A wide variety of different survey-based methods have been utilized and/or developed in the excellent series of papers published in this issue of the *Journal on Developmental Disabilities*. For the benefit of people about to enter the research field or undertake an activity called outcome analysis to evaluate the efficacy of treatment or service, we thought it might be helpful to provide a brief overview of concepts underlying the development and testing of questionnaires, surveys and instruments for use in the intellectual and developmental disabilities field. As well, we have provided a bibliography of references and internet resources that we have found to be useful. Remember that research findings can be no better than the quality and nature of the data that are collected, and that the quality of data depends upon the validity and reliability of the methodology!

Two key characteristics important in the development and testing of surveys, questionnaires, or instruments are establishment of their validity and reliability. Validity refers to whether the instrument measures what it intends to measure and describe.

Reliability refers to the reproducibility of the measures. A reliable questionnaire or instrument is one that that would give the same results if used repeatedly with the same group.

Validity is more difficult to establish than reliability, and depends first and foremost on reliability. A measure can be reliable but not valid, but to be valid a measure must be reliable. For example, if a questionnaire is supposed to measure depression, then its application should correctly identify actual depression and not other problems that may mask as depression such as hypothyroidism. Validity also depends upon how a survey instrument is employed. For example, results may not be the same for a telephone interview, a face to face interview, a written questionnaire, an online questionnaire, or a focus group.

Statisticians have devised tests of reliability for questionnaires. For example, there are different approved ways for measuring reliability such as *test-retest*, *equivalent forms*, *split-half*, *Cronbach's Alpha* and *factor analysis*. Some issues to consider in making a questionnaire reliable are: Does it control for different response patterns (for example is a “3 out of 5” for one person the same as a “3 out of 5” for another; Is there an effect of an issue’s position in a survey; Is it possible to detect cooperation between individuals in a single response; Does the questionnaire measure the variability of each question or issue; Can it identify respondents who have difficulty understanding questions or instructions because of language, literacy, and/or neurocognitive issues.

Questionnaires and surveys can range from well known and fully characterized tools, to ones devised by individual researchers to address very specific issues. Many different test and assessment instruments have been standardized for the evaluation of cognition and behaviours of individuals in the general and/or majority population. However, such standardization does not necessarily mean that they can be used with minority groups in the general population, in different countries, or, as is particularly relevant here, for the evaluation of people with intellectual and developmental disabilities, without additional standardization or modification.

The development and testing of a questionnaire or instrument can be a time-consuming and challenging process. If it is intended for people with developmental disabilities, the language used must be simple, and consideration should be given to asking the same question twice in different ways and/or times to ensure that questions have been understood. The “readability statistics” function of the spelling and grammar tool of Microsoft Word is useful for determining the language level of a document. Often, inadequate attention is given to questionnaire development and testing compared with the time and resources used to collect information. Effort put into data gathering should match the importance of the decisions that need

to be made. Data should be gathered from all people who can contribute useful information even if this is difficult to do. The importance of including the knowledge and views of individuals with intellectual and developmental disabilities, themselves, is accepted today as a very valuable source of information. Although this frequently poses challenges to research design, it is far from impossible and can be done effectively. Finally, respondents need to be able to answer a questionnaire knowing that the information provided will remain confidential. This cannot be assumed without the deliberate introduction of administrative procedures to protect confidentiality.

One question that should always be foremost in the mind of a researcher or reader of a research paper or report is whether or not the instrument used for data collection has sufficient validity and reliability. Perhaps this is not so important in small pilot studies that ask if an issue is worth pursuing in depth, though it certainly is for studies such as determining if expensive service programs funded by the government are effective and if their quality is adequate. Researchers sometimes assume that if you use a validated instrument, the results of a study that utilizes such an instrument will be valid and reliable, but this is not necessarily so. Conversely, a beautifully designed study can be hampered by the use of a poor data collection instrument. Aside from the methodology that is employed, in all forms of research, the definition of terms, the description of the research approach, and a sound plan for data analysis and interpretation are essential to ensure that others can repeat the study and obtain similar findings.

Research in our field is usually thought of in terms of collection of data that is either quantitative or qualitative in nature. Quantitative information is exclusively numerical or quantifiable. Qualitative information emerges from the use of a variety of methods, and from a variety of media, including written or spoken words, sound, images, videos, performance, and inspection of objects (e.g., tissue sections on a microscope slide for abnormal features). Collection of quantitative data often requires large random samples. As well, how the sample is selected, the nature of the sample, and sample size, are very important. In contrast, qualitative research may involve a sample size that is large, or smaller but focused. To note is that it is not always possible to apply the concepts of validity and reliability to a method that generates qualitative data. Qualitative research frequently involves categorization of data into patterns as the primary basis for organizing and reporting results. In this case, it is important that the data are authentic, credible, and if possible transferable in the sense that the general principles that emerge from analysis are also pertinent to other people or groups. In this case, analysis of the collected data requires evaluation by two or more investigators. The

research papers in this issue of the Journal use a wide array of survey-based procedures for the collection of qualitative and/or quantitative data.

Doan, Martin, Yu and Martin characterize the ability of the well-characterized Assessment of Basic Learning Abilities (ABLA) test to predict three-choice task performance. The ABLA includes only two-choice tasks, which are not always reflective of real-life situations. By showing that ABLA can predict three-choice task performance, ABLA's predictive validity is thus strengthened.

Jones, Minnes, Elms, Paret and Vilela use the Novaco Anger Scale and Provocation Inventory (NAS-PI) to determine if a community-based anger treatment group for individuals with dual diagnosis has been effective. Although the sample size was small and the results of only five pre- and post-participation assessments by care providers were available, results of this pilot study were encouraging.

Jozsvai, Gajdos, Lean and Hewitt employ a simple survey that they devised to collect pilot information about tobacco use and alcohol/drug problems among adults with developmental disability in Ontario, and availability of treatment options for substance abuse. Tobacco, alcohol and cannabis use were found to be surprisingly common in the population surveyed. In addition, the majority of service providers who responded thought that treatment options for substance abuse were not adequate to meet the needs of those with alcohol or drug problems.

The issue of sexuality is a major concern for parents of children with developmental disabilities world-wide. The two papers by Karellou describe the development and application of a scale for collecting information about the attitudes Greek parents have about sexuality in general and in their own offspring with developmental disabilities, and the application of this tool to a series of 100 Greek parents. Perhaps not surprisingly, level of education surfaced as a key factor affecting attitudes about sexuality.

The two papers by Martin, Hirdes and Fries utilize information from the well-characterized Resident Assessment Instrument-Mental Health (RAI-MH) and Resident Assessment Instrument 2.0 (RAI 2.0) to understand the characteristics and service utilizations of people with developmental disabilities receiving psychiatric or chronic care hospital services in Ontario. Both assessment instruments identify key clinical issues related to care planning, quality improvement and outcome measurement, and have been extensively tested in the populations for which they were designed. Persons with developmental disabilities access these types of healthcare services,

though they may not present as the “typical” patient. The papers by Martin et al. identify discrepancies that exist between identified needs and services that are in place for people with developmental disabilities receiving psychiatric or chronic care, especially for those with aggressive behaviour problems or functional impairment in activities of daily living. This could be a result of the lack of overall familiarity of clinicians and staff with developmental issues. Information from these papers provided the impetus for development of a new RAI instrument to be used in the developmental sector, called interRAI Intellectual Disability (interRAI ID), which could be used to improve communication between providers in social and health sectors, as well as provide baseline information to clinicians of pre-morbid abilities and status.

The paper by Minnes, Lauckner and Recoskie is an exemplary demonstration of how to analyze qualitative information collected from a focus group. In this case, a focus group involving eight primary care providers was used to identify three important issues relating to doctors involved in the care of children with fragile X syndrome. Doctors need more education about this common genetic disorder. They need to take extra time to provide information and care that is needed. Finally, the trait of patience is essential when dealing with affected children and their families.

In Ontario, intensive behavioural intervention (IBI) is the treatment of choice for young children with autism. It already is known that outcome depends upon the quantity of such treatment, but there is no information about the possible importance of treatment quality. Penn, Prichard and Perry present information about the reliability and validity of a pilot version of an instrument called the York Measure of Quality of IB (YMQI). Although the results were promising, the authors conclude that more development is needed before the instrument can be used for reliable and valid data collection.

The epidemiological study by Ouellette-Kuntz and Burge uses a telephone survey specifically developed to collect information from a large representative sample of the Ontario public regarding perceptions about the best form of community living arrangements for people with developmental disabilities. The majority of respondents believed that supervised apartments or group homes would work best. Lack of community services was identified as a major obstacle to the inclusion of people with developmental disabilities into the community.

The paper by Gill and Renwick addresses the under-researched topic of the importance of quality of life for families of adults with developmental disabilities and issues relating to availability and provision of services. This

paper uses secondary analysis of a set of interview data that was previously collected as part of a larger family quality of life project in an approach called modified grounded theory. Themes that were identified include lack of coordination of services, lack of information about services, long waiting lists for services, and lack of availability of adequate services.

The final three papers in this issue of the Journal include two review papers that contain new insights developed by the authors and one case report. McLaren describes the new treatment approach of deep brain stimulation and explains how it possibly might benefit people with autism who suffer from intractable seizures. Phan provides an introduction to use of the ketogenic diet in intractable epilepsy, and provides insight about why this approach may work in instances where other methods for management have failed. The case report by Savage and colleagues explains how a medical problem can mask as a mental health disorder and how important it is to have the care of a person with dual diagnosis managed by a multidisciplinary team.

For information, some references generally relevant to questionnaire and survey design and related methodology that may be helpful to prospective researchers are provided.

*Chief Editorial Committee*

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