Evidence-based Practice in Developmental Disabilities: What is it and Why Does it Matter?

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Editors' Note: As recipient of the 2005 OADD-RSIG Professional Award for Excellence in Research, and Friday morning keynote speaker at the 2005 Annual OADD conference, Adrienne Perry spoke about the importance of evidence-based practice in the field of developmental disabilities. This is a summary of that keynote address.

We all want to do the best job possible with the clients/students/ consumers/people we support. Evidence-based practice is all about helping us do that. That's why it matters.

In our experience, Ontario is fortunate to have many caregivers and therapists who are interested in up-to-date research findings, as well as researchers who are scientist-practitioners in the developmental disabilities (DD) field. In terms of evidence-based practice, the ground is fertile and well-cultivated, the seed is sown, and the crop is already growing in many parts of the field. Our task is to encourage this growth even more, throughout the field.

So what is Evidence-based Practice? It can be defined as "the conscientious, explicit and judicious use of current best evidence in making decisions about the care of [clients]" (Sackett, Richardson, Rosenberg, & Haynes, 1997, p.2, as cited in Barwick, et al., 2005, p.7). Thus, it is similar to several other terms that involve using research evidence to inform practice and client care, including: data-based approaches, empirically-supported treatment, best practices, empirically-validated treatment, clinical practice guidelines, and evidence-based medicine.

The term "evidence-based" itself has recently burgeoned in the scientific/professional literature, demonstrating its growing influence. For example, prior to 1990, there appears to be no use of the term at all and, between 1990 and 1995, it is found only 86 times in the literature (Hoagwood & Johnson, 2003). A search of the PsycINFO database from 1995-1999 reveals 225 references, while from 2000 until spring 2005, there were an overwhelming 2,125 references. There has also been an astounding increase in public use of the term, as shown by a Google internet search in April 2005 which found 4,580,000 results, while the same search in August 2005 finds 6,690,000 results.

There are many sets of guidelines for different aspects of evidence-based treatment, mostly of a fairly medical nature (see www.guideline.gov). Somewhat more relevant for our purposes, there are a number of treatments within the field of children's mental health that can be characterized as being "evidence-based", in that they have been developed through research and supported by controlled studies (Barwick, et al., 2005; see Table 1). Unfortunately, a similar list of evidence-based treatments specialized for individuals with developmental disabilities does not exist. The closest set of guidelines available is a recent review on evidence-based practice in autism spectrum disorders (Perry & Condillac, 2003). This review highlights that some popular approaches have little if any good evidence behind them and this may well be the case for the DD field more generally.

Table 1.   Evidence-based treatments in children's mental health in Ontario

- Aggression Replacement Training
- Brief Strategic Family Therapy
- Bullying Prevention Program
- Behavioural Parent Training
- Behavioural Teacher Training
- COPE
- Cognitive Behaviour Therapy (CBT)
- Earlscourt Under 12 Outreach Program (ORP)
- Earlscourt Girls Connection
- Family Effectiveness Training
- Families and Schools Together (FAST)
- Functional Family Therapy (FFT)
- Good Behaviour Game
- Helping the Noncompliant Child
- Homebuilders
- I Can Problem Solve
- Intensive Behavioural Intervention (IBI)
- Linking the Interests of Families and Teachers (LIFT)
- Life Skills Training
- Multidimensional Treatment Foster Care (MDTFC)
- Multisystemic Therapy
- Narrative Therapy
- Nurse-Family Partnership
- Perry Preschool Program
- Positive Behaviour Support (PBS)
- Project Towards No Drug Abuse (Project TND)
- Promoting Alternative Thinking Strategies (PATHS)
- Psychopharmacology

continued

Table 1.   (cont'd)

- Right from the Start
- School Transitional Environmental Program (STEP)
- Stop Now and Plan (SNAPP)
- Teaching Family Model
- The Incredible Years
- Wraparound

from Barwick et al., 2005, p. 82

New interventions and treatments arise frequently and, while they may make interesting claims, they may or may not be evidence-based. Therefore, everyone working in the DD field should learn the basics about how to understand and evaluate evidence, or at least what basic questions to ask, such as: What constitutes evidence? Does the theory behind the approach make sense? Is the intervention individualized, based on assessment? What training is required? Does it include some form of data collection and ongoing supervision? What are the costs/risks and possible side effects for the client, family, staff, or agency (including money, time, energy, and expectations)? What are the potential benefits? Will it make a difference to the client's quality of life? What is the quantity and quality of the evidence? We must be sure that our examination of evidence regarding particular treatment methods is guided by our values (i.e., helping people with developmental disabilities), by the particular context and issue, by common sense, and by the critical evaluation of the strengths and limitations of different types of evidence to answer different questions.

Many readers may be thinking that their work doesn't really fit into a treatment framework and this is an important point. It can be argued that the nature of our work is different from that in medical or mental health arenas, in that it is much broader and does not only involve providing "treatment". Treatment implies a medical model view of our clients and a goal of curing a disease or disorder, and in our field this is often not appropriate. Instead, treatments or interventions are often used to eliminate or reduce the intensity of specific symptoms, not the disability in general. Moreover, interventions and approaches are used to teach skills and habilitate clients. We often strive to implement supports to enhance the quality of life and community participation of persons with DD, as well as support their family members and others in their environment. These efforts, integral to providing care for individuals with DD, do not easily lend themselves to the conventional notion of treatment.

Therefore, our goal should not be to use evidence-based treatment, but rather to think more generally in terms of evidence-based practice, which includes a broader frame of reference and range of actions. As Barwick and colleagues (2005) noted: "Placing the client's benefits first, evidence-based practitioners adopt a process of lifelong learning that involves continually posing specific questions of direct practical importance to clients, searching objectively and efficiently for the current best evidence relative to each question, and taking appropriate action guided by evidence" (p.7).

Certainly, professionals in the developmental disabilities field have historical precedent for assuming an evidence-based culture. There is a tradition of using data in our practice to help us make clinical decisions with regard to individual client progress, but this notion of evidence-based practice goes beyond that and can be applied to many aspects of our work. We can ask ourselves, how do we use data to assist us in making decisions about eligibility for services or deciding whom to admit from the wait list? How do we use evidence and professional consensus to select assessment measures that are reliable, valid, and clinically useful? What types of intervention do we use or stop using, based on the evidence available? In our work of educating, supporting, and treating people, are we confident that we are using primarily solid, evidence-based methods? Are we collecting data and using it to guide our decision-making regarding individual clients and about our services generally? Are we sharing our data with relevant stakeholders and the rest of the field?

We want to encourage and support evidence-based practice where it is already flourishing and to nurture its growth where it is still germinating in the DD field in Ontario. In so doing, we might consider whether there is a role for the Ontario Association on Developmental Disabilities and/or its Research Special Interest Group in commissioning or producing a set of evidence-based practice guidelines or in promoting evidence-based practice in other ways. As an association that involves professionals with a large array of specializations, OADD contains the collective expertise of people who work directly with individuals with developmental disabilities, a tremendous amount of clinical experience, and the knowledge that is gained from research. Our Conference is one example of an opportunity to share information from different perspectives, as is this Journal, and perhaps other vehicles are also needed.

To this end, it is critical that we consider what is needed in the field in terms of knowledge transfer and training in evidence-based practice. It is well-established that the existence of the knowledge or of best practice guidelines

does not necessarily translate into practice (Barwick et al., 2005). Dissemination has to be deliberate; communication and partnership between researchers and clinicians and among specializations is necessary. Finally, we have to work around or through the very real barriers and challenges to implementing evidence-based practice. There are resource pressures (e.g., staff, money, time, space) and service pressures (e.g., having to see more clients, reduce wait lists, etc.). Capacity building requires time and implementing organizational change is never easy. Yet, it is our responsibility to proceed nonetheless.

As members of OADD, we all share a common goal of improving the lives of individuals with developmental disabilities and those whom they touch. At the heart of it, evidence-based practice means that we question what we do so that we can help clients be the best they can be. We collect evidence to evaluate our work and we strive to be open to the answers we get (even if we do not like them). We make decisions based on the best data available (taking into account its possible limits) and we share our knowledge with others and learn from each other. The field is cultivated and planted, the crop is growing well in places. Together, we can continue to water and nourish the crop, encourage cross-fertilization, and promote long-term sustainability, for the benefit of the people with developmental disabilities that we treat, teach, support, and love.

References

Barwick, M. A., Boydell, K. M., Stasiulis, E., Ferguson, B., Blasé, K., & Fixsen, D. (2005). *Knowledge transfer and evidence-based practice in children's mental health.* Toronto, ON: Children's Mental Health Association. www.cmho.org

Hoagwood, K., & Johnson, J. (2003). School psychology: A public health framework I. From evidence-based practices to evidence-based policies. *Journal of School Psychology, 41*, 3-21.

Perry, A., & Condillac, R. A. (2003). *Evidence-based practices for children and adolescents with Autism Spectrum Disorders: Reviews of the literature and practice guide.* Toronto, ON: Children's Mental Health Ontario. www.cmho.org

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