Using a Knowledge Translation Lens to Develop International Collaborations to Improve the Health of Individuals With Intellectual Disabilities


*Queen’s University, Kingston, ON, Canada; †The Children’s Hospital at Westmead, University of Sydney, Westmead, NSW, Australia; ‡Monash University, Notting Hill, VIC, Australia; §Lancaster University, Institute for Health Research, Lancaster, UK; ¶Cardiff University, Cardiff, Wales, UK; **University of Maastricht, Maastricht, The Netherlands; ††Westchester Institute for Human Development, Valhalla, NY, USA; ‡‡Centre de réadaptation en déficience intellectuelle Gabrielle-Major, Montreal, QC, Canada; §§University of Sydney, Sydney, NSW, Australia; and ¶¶Radboud University Medical Centre, Nijmegen, The Netherlands

Abstract This report describes the process used at the International Association for the Scientific Study of Intellectual Disabilities Health Issues Special Interest Research Group’s 2009 Roundtable to increase awareness of the importance of, and opportunities for, knowledge translation to improve the health of individuals with intellectual disabilities (ID) through international collaboration. The “knowledge-to-action cycle” (i.e., knowledge translation) formed the basis for the roundtable discussions. The thematic areas discussed included identification and reduction of disability in adults who also have epilepsy, obesity in children and adults, adapting health promotion materials and approaches, and policy and practice healthcare management—all related to individuals with ID. The topics were explored, extant information presented, and agreements reached for further work and collaborations in each of the topic areas. It was noted that the roundtable’s use of the knowledge-to-action framework helped the participants focus on bringing together existing knowledge in ways that can meaningfully influence policy and practice. A pre-workshop web-based forum allowed participants to share information and recognize the need for synthesis and tool development. Multidisciplinary working groups that are international in scope can be useful in continuing to work toward increasing awareness of the knowledge-to-action cycle and promoting collaborative health research in the area of health and ID.

Keywords: collaborations, health issues, intellectual disabilities, knowledge translation, roundtable

INTRODUCTION

The Canadian Institutes of Health Research and the U.S. Centers for Disease Control and Prevention have identified disabilities, including intellectual disabilities (ID), as a primary source of health inequalities (Krahm, Fox, Campbell, Ramon, & Jesien, 2010). A report from England highlights the tragic consequences of the failure to implement recognized best practices in the field of ID (Mencap, 2007). The gap between knowledge and practice has been addressed by researchers who have developed models of applying and evaluating the use of research results (Graham et al., 2006). Knowledge translation is one term used to describe this process and is defined as “the exchange, synthesis and ethically-sound application of knowledge—within a complex system of interaction among researchers and users—to accelerate the capture of the benefits of research . . . through improved health, more effective services and products, and a strengthened healthcare system” (Canadian Institutes of Health Research [CIHR], 2009). There is a need to formalize the process of knowledge translation in the field of ID.

Although researchers in the field of ID have certainly taken part in the phases of knowledge translation, it has rarely been acknowledged or systematically studied as a formal process in the ID literature. There are exceptions—most notably in Australia and in the UK. McConnell, Matthews, Llewellyn, Mildon, and Hindmarsh (2008) discussed an initiative undertaken to reduce the risk associated with being the child of a parent with an ID by providing appropriate supports and services to the family. The authors noted an apparent gap between research and practice, whereby the services identified as being useful to protect these families were underdeveloped, scattered, and of variable quality. The goal of their program—“Healthy Start”—was to facilitate organizational and practitioner adaptation of knowledge and
research to meet community-specific needs. This was accomplished by disseminating knowledge to local area networks that were linked by a national technology-based network. The main strategies for turning knowledge to action were capacity building, leadership and managerial support, access to knowledge, peer networking, and adaptation to the local context. By building interest in and ability to use research at the local level, they were able to ensure translation of research findings into practice.

An initiative in the UK, called “Making Research Count,” was established in 1997 with the goal of facilitating access to social care knowledge (for ID, physical disability, and mental illness) by agency practitioners and managers (Blewett, 2007). This was accomplished by establishing close relationships between university-based coordinators and “link officers” in each agency in order to enable engagement between agency staff and researchers. Blewett (2007) identified a number of challenges to getting practitioners to see the value of implementing research-based findings, but noted that it was collaboration between practitioners and researchers, through all stages of research and application, that made the process work. Through their alliances, they were able to facilitate knowledge uptake.

Similarly, in Ireland, Canavan, Gillen, and Shaw (2009) discussed a study to determine the needs of individuals with ID so as to define the future nature of service provision within the country. They saw this as an example of measuring research impact. The study involved close partnerships between researchers and service planners. Consideration of the impact was planned into the effort by commissioning research at a high level of the service system (i.e., the service provider was involved in defining the scope of the research). Results were distributed to politicians, service providers, service users with ID and their parents, and trade unions. The goal was to ensure availability of results and to facilitate use of research findings. Like Blewett, Canavan, et al. (2009) argued for a partnership approach to research.

The above examples illustrate how researchers in the field of ID have been able to deliberately incorporate models of knowledge translation into their research in order to ensure that their findings are applied to the local context. Given that there is so often a gap between research and practice, it is time for this systematic integration of knowledge translation principles to be included in other research in the field of ID.

**Aims and Process**

The aim of this report is to describe the process used at the International Association for the Scientific Study of Intellectual Disabilities (IASSID) Health Issues Special Interest Research Group’s 2009 Roundtable to increase awareness of the importance of, and opportunities for, knowledge translation to improve the health of individuals with ID through international collaboration.

The Health Issues Special Interest Research Group’s mission is to promote the physical health of individuals with ID by developing priorities for research, training, and healthcare. This is accomplished through the sharing of ideas and results at roundtable meetings held annually. The 2009 meeting, titled “International Collaboration to Improve the Health of Individuals with Intellectual Disabilities,” was held at Queen’s University in Kingston, Ontario, Canada. The 75 participants included researchers, policy makers and service providers, students and staff, and persons with disabilities. Participants were from Asia, Australia and New Zealand, Canada, Europe, and the U.S.; a mix which ensured international representation as well as engagement of a wide scope of parties who would have interests in knowledge translation.

The knowledge-to-action cycle (i.e., knowledge translation) described by Graham et al. (2006) formed the basis for the roundtable discussions. Knowledge translation is understood as a dynamic process characterized by engagement of stakeholders/partners in various ways at different points in the process from knowledge creation to action. Briefly, the knowledge creation portion of this cycle encompasses the processes of knowledge inquiry (e.g., primary studies), knowledge synthesis (e.g., systematic reviews), and the creation of knowledge tools or products (e.g., practice guidelines). Once knowledge products have been created, the action phase begins. This phase comprises adapting knowledge to the local context, assessing potential barriers to knowledge use, implementing interventions to promote knowledge use, monitoring knowledge use, determining the impact of knowledge use on the problem, and sustaining knowledge use. Moreover, the knowledge creation and action phases affect and are affected by each other as knowledge in the field grows and influences practice which, in turn, reveals questions which need to be answered by further research (Graham et al., 2006).

To facilitate the development of actionable items as a result of the roundtable, an international multidisciplinary planning committee (H. Ouellette-Kuntz, M. Meijer, D. O’Hara, D. Morin, and D. Elliott) sought and vetted workshop proposals from IASSID members and grouped submissions to form four workshops dealing with significant health issues in the field of ID—see Table 1. The workshops were led by researchers and clinicians from the UK, the Netherlands, Australia, Canada, and the U.S.

Prior to the roundtable, a web site was created that contained roundtable details and forums for sharing resources. To establish the state of the science in each theme area, a catalogue of relevant references was developed and distributed to participants. These bibliographies are available from the corresponding author. Over the course of the 2.5-day roundtable, participants took part in one of the concurrent workshops and came together as a group at the start of each day to review and discuss emerging plans.

**ROUNDTABLE ACTIVITIES**

**Knowledge Creation and Synthesis**

The roundtable workshops were focused on producing outcomes that would further the process of knowledge translation in the field of ID. Some were focused on knowledge creation phases. For example, the obesity group developed some outcomes that were focused specifically on knowledge inquiry. They committed to engaging with obesity researchers to develop a set of key questions or measurement tools that would enable improved
<table>
<thead>
<tr>
<th>Topic</th>
<th>Leaders</th>
<th>Commentary</th>
<th>Aims</th>
</tr>
</thead>
<tbody>
<tr>
<td>The identification and reduction of disability in adults who have epilepsy and an intellectual disability</td>
<td>M. Kerr &amp; J. Perry</td>
<td>The bases for the discussion of this workshop were drawn from the recognized disparity between the needs of individuals with epilepsy and ID and the services and supports that they receive (Hanna et al., 2002).</td>
<td>The workshop aimed to: (1) gain an understanding of the disability caused by epilepsy in people with ID, (2) gain an understanding of the treatment modalities which may reduce epilepsy-related disability in people with ID, and (3) develop a draft tool to identify potential treatment gaps in people with ID and epilepsy.</td>
</tr>
<tr>
<td>Obesity in children and adults with an intellectual disability</td>
<td>J. Small, E. Emerson, &amp; L. Baur</td>
<td>The bases for discussions within this topic were the key themes that emerged from existing literature (e.g., Melville, Hamilton, Hankey, Miller, &amp; Boyle, 2007).</td>
<td>This workshop aimed to: (1) stimulate high-quality research in obesity in ID, particularly that involving international collaborations; (2) develop agreed priorities for research and advocacy; and (3) seek to advocate for the inclusion of people with ID in mainstream obesity research.</td>
</tr>
<tr>
<td>Adapting health promotion materials and approaches for individuals with an intellectual disability</td>
<td>R. Davis, R. Proulx, &amp; D. O’Hara</td>
<td>The Nutbeam, (1998) outcome model on population health promotion and core competencies for health promotion derived from the Galway Consensus Conference (Barry, Allegrante, Lamarre, Auld, &amp; Taub, 2009) were used to guide discussions in this area.</td>
<td>This workshop aimed to: (1) review existing research in health promotion for people with ID; (2) identify key issues that would benefit from health promotion activity in people with ID; (3) develop an understanding of the key issues in research and health promotion in the general population and within other disadvantaged populations; and (4) establish opportunities to link with research and practice in the general population. The participants focused on two issues: (1) health promotion strategies that are effective for a general population may not work well for people with ID; and (2) the existing literature on health promotion and ID is not very accessible nor easy to retrieve and thus not available for translation into practice.</td>
</tr>
<tr>
<td>Healthcare management for individuals with an intellectual disability: policy and practice</td>
<td>H. van Schrojenstein Lantman-de Valk &amp; M. Meijer, with P. Manners &amp; J. Blair</td>
<td>The best way to organize healthcare services for persons with ID has been debated since the deinstitutionalization of services for people with ID. The organization of healthcare for persons with ID in the world seems to be a matter of local circumstances; services are shaped by the health service system in the particular jurisdiction. While in the Netherlands a specialist physician for persons with ID became a new registered specialization, the UK retained its “learning disability” psychiatrists and Australia developed special programs for general practitioners and nurse practitioners, and initiated health monitoring programs.</td>
<td>This workshop aimed to: (1) establish international collaboration in research and in the dissemination of evidence-based healthcare services for persons with ID and (2) identify fundamental requirements of healthcare systems to ensure optimal outcomes for those with ID.</td>
</tr>
</tbody>
</table>

ID = intellectual disabilities.

Note: Mike Kerr, MD, was responsible for the “identification and reduction of disability in adults who have epilepsy and ID” (kerrmp@cf.ac.uk); Jacqueline Small, MD, was responsible for “obesity in children and adults with ID” (jacquels@chw.edu.au); Robert Davis, MD, was responsible for “adapting health promotion materials and approaches for individuals with ID” (robert.davis@med.monash.edu.au); and Henny van Schrojenstein Lantman-de Valk, MD, PhD, was responsible for “healthcare management for individuals with ID: policy and practice” (h.lantman@elg.umcn.nl).
identification of people with ID in both adult and child population surveys that collect data on obesity. This is seen as a critical step in tracking prevalence of obesity in persons with ID across different geographic populations and over time. It was felt the lack of this basic knowledge impeded the development of more relevant and informative research.

Other groups focused more on knowledge synthesis, whereby existing knowledge is aggregated in the form of reviews. The epilepsy study group was one example. Using existing research combined with expert opinion of the participants, the group was able to identify a list of "red flags" to be used in a care or clinical setting as identifiers of a potential care or treatment gap for an adult with ID and epilepsy. These would consider such things as: seizure history and current status, investigation history and current status (e.g., use of electroencephalogram or seizure diary), treatment history and current status, investigation of medication side effects, access to specialists, presence of problem behaviors or mental health issues, injury history, and peri-ictal behavior and mood. One of the outcomes of the workshop was to develop a consensus statement on identifying unmet need in community practice settings for people with epilepsy and ID that will be submitted to an appropriate journal.

The health promotion study group also focused on knowledge synthesis. Their intent was to establish an international consensus among researchers about data that should be collected to measure the health outcomes of people with ID and to lobby the constituencies responsible for collecting that data. In this way, they will be able to aggregate relevant existing knowledge in order to determine the direction that future health promotion research in the field of ID should take.

Finally, the health services study group also focused on knowledge synthesis. Based on previous literature (Meijer & Scholte, 2004; van Schrojenstein Lantman-de Valk & Walsh, 2008) and the workshop discussions, the group was tasked to develop: (1) an overview of available healthcare services for persons with ID; (2) a summary of the workshop in the form of a manuscript; (3) background documents on advocacy and transition; (4) and an updated Cochrane review on organizational interventions in health relevant to persons with ID (Balogh, Ouellette-Kuntz, Bourne, Lunsky, & Colantonio, 2008). These outcomes also represent knowledge synthesis and will enable researchers to determine what is known about health services for individuals with ID and where improvements should be made.

Within the knowledge creation phase, there were also knowledge tools and products that the groups aimed to develop. For example, the epilepsy study group agreed to carry out further research to explore the impact of the "red flag" tool described previously and investigate its potential to identify and reduce health disparity. In this way, they will be able to present knowledge in a clear, concise, and user-friendly format that can be used by practitioners.

Likewise, based on workshop discussions, the obesity study group agreed to establish collaborations that address the development of a framework for understanding obesity in people with ID that could form preventative interventions (e.g., through focusing on the emergence of increased risk for obesity in the early childhood years). This group will therefore be able to use existing knowledge to develop guidelines that are useful for practice.

Action Cycle

Other workshop outcomes were focused more on the action cycle. Specifically, the health promotion study group hoped to address barriers to knowledge use by building new or extending partnerships with key stakeholders to work to improve access to health promotion activities as well as ensuring that health promotion activities for the general population are made accessible to people with ID. Thus, they hope to assess factors that may impede or facilitate knowledge uptake.

Several workshop outcomes were focused on selecting, tailoring, or implementing interventions to improve knowledge uptake. The obesity study group hoped to provide a report for, along with direct engagement with, international organizations (e.g., International Association for the Study of Obesity, a peak international body for research and advocacy for obesity; World Health Organization) to demonstrate the risk and needs of obese people with ID. They also aimed to develop a position statement, to be published, that will support further advocacy and planning of research. In this way, they will be able to apply knowledge from the field of ID to organizations that focus on obesity in general, in order to ensure that individuals with ID are seen as a priority for intervention.

Likewise, the health promotion study group aimed to develop a statement that provides a framework for understanding the need for an enabling physical and interpersonal environment for health promotion that is supported by a strong evidence base. This is an outcome that will promote awareness of knowledge and research results and will provide a basis for better planning in the future by services outside the traditional health sector, but which clearly impact on health outcomes.

Finally, the healthcare delivery study group wished to develop a statement endorsed by the IASSID regarding equal access to healthcare for individuals with ID. Again, this outcome is focused on creating awareness of the inequalities affecting individuals with ID, and by doing so, aims to facilitate change and improvement in the healthcare delivery system.

In terms of monitoring knowledge use, the health promotion group recognized that evidence-based and accessible health promotion resources are fundamental requirements for best practice. To this end, they plan to develop a central review process about health promotion materials that includes people with ID as reviewers. In this way, they would be able to reassess the likelihood of use of knowledge. In addition, by involving people with ID in the process, they will be able to adapt knowledge to the local context.

CONCLUSION

The roundtable’s use of the knowledge-to-action framework helped the participants focus on bringing together existing knowledge in ways that can meaningfully influence policy and practice. The pre-workshop web-based forum allowed participants to share information and recognize the need for synthesis and tool development. Multidisciplinary working groups which are international in scope are continuing the work begun in Kingston. Reports of their activities and outcomes will be shared at
future meetings and in relevant publications. Increasing awareness of the knowledge-to-action cycle will serve health research in ID well into the future.

ACKNOWLEDGMENTS

Major sponsors of the roundtable were the Canadian Institutes of Health Research (Meetings, Planning, and Dissemination Grant #92722), the U.S. Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities (NCBDDD) under Cooperative Agreement U01DD000231 to the Association of University Centers on Disabilities, and the Public Health Agency of Canada (Contract # 4500211876). Additional sponsors were: the IASSID-Health Issues Special Interest Research Group, Queen’s University, the South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities, the St. Amant Research Centre (Manitoba), the Community Networks of Specialized Care—East Region (Ontario), the American Association of Intellectual and Developmental Disabilities—Québec Chapter, the Canadian Association for Research and Education in Intellectual Disability, and the Center for Addiction and Mental Health (Ontario). The content of this manuscript does not necessarily reflect the views and policies of any of the sponsors.

REFERENCES


