

Facilitating and Impeding Factors for Knowledge Translation in Developmental Disabilities: Outcomes of Community-Based Workshops

Abstract

We held three community workshops to strengthen partnership and commitment for knowledge translation (KT) in developmental disabilities (DD), and to learn about contextual factors that facilitate and impede KT. Sixty-four administrators, parents, policy-makers, practitioners, and researchers participated. We introduced a conceptual framework for KT, conducted assessments of KT capacity, discussed contextual facilitating and impeding factors, and considered ways to improve KT. We found that all participants highly valued research, but organizational mission statements, policies, and job descriptions do not always prioritize research; lack of time, incentives, and resources were cited as impediments to KT. Researchers were advised to develop projects collaboratively with practitioners, and to disseminate findings using channels accessible to the general public.

Persons with developmental disabilities (DD) are those who “have significantly greater difficulty than most people with intellectual and adaptive functioning and have had such difficulties from a very early age. Adaptive functioning means carrying out everyday activities such as communicating and interacting with others, managing money, doing household activities and attending to personal care” (National Coalition on Dual Diagnosis, 2008). DD is often used by researchers as a broad term to include a range of diagnoses such as mental retardation, Down syndrome, and autism (Conyers, Martin, Martin, & Yu, 2002). Research in DD addresses many areas, including genetics, diagnosis, co-morbidities, learning and education, independent living, health and well-being, employment, socialization, recreation, aging, and palliative care. Research findings can inform policy and practice only if made accessible to potential users in a timely manner, in understandable language, and in a user-friendly format. This is the idea behind knowledge translation (KT). The Canadian Institutes of Health Research (CIHR, 2004) defines KT as “the exchange, synthesis and ethically-sound application of knowledge—within a complex system of interactions among researchers and users—to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system.”

Although KT is an essential part of best practices in health care, KT in DD has received little attention in the research literature. In 2008 the interdisciplinary research team at

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St. Amant Research Centre responded to this situation by holding three workshops in Winnipeg, Manitoba (Canada) with stakeholders and researchers in DD. The first session was a full-day facilitated workshop on June 9. Next, we hosted a 90-minute session at the 17th Annual St. Amant Conference on Intellectual/Developmental Disabilities on October 6. Finally, we held a half-day facilitated workshop on December 2.

Objectives

The objectives of each workshop were to: (a) strengthen partnership and commitment for KT in DD, and (b) learn from stakeholders about research priorities and contextual factors that facilitate and impede KT.

Method

Participants and Setting

We identified 70 individuals representing over 20 organizations as potential stakeholders and sent them an invitation to participate in one of the workshops. Other stakeholders attended the St. Amant Conference session on an open, non-invitation basis. In total, 64 individuals from Winnipeg and rural areas in Manitoba participated. These individuals were asked to identify themselves as representing the perspective of one of four stakeholder groups: Administrators & Policy-makers ($n = 16$), Parents ($n = 10$), Practitioners ($n = 17$), and Researchers ($n = 21$).

Procedure

All workshops consisted of four key components:

1. *Introducing the KT concept*

To provide a context for the subsequent discussion, particularly for participants not previously familiar with the KT concept, a St. Amant Research Centre team member presented the CIHR conceptual framework for KT (National Center for the Dissemination of Disability Research, 2007) with concrete examples.

2. *Assessing the participating organizations' and individuals' KT capacity*

We used a 27-item self-assessment tool developed by the Canadian Health Services Research Foundation (CHSRF, 2005) to measure the KT capacity of participants and their organizations. There were four general assessment areas: (a) *Acquire*—12 items related to finding and obtaining required research information, e.g., “Our staff has enough time for research.”; (b) *Assess*—4 items related to assessing research findings to ensure they are reliable, relevant, and applicable, e.g., “Staff in our organization have critical appraisal skills and tools for evaluating research quality.”; (c) *Adapt*—4 items related to presenting research to decision makers in a useful way, e.g., “Our organization has arrangements with external experts who use research communication skills to present research results concisely and in accessible language.”; and (d) *Apply*—7 items related to using skills, structures, processes, and organizational culture to promote and use research findings in decision-making, e.g., “Research is accessed, adapted, and applied in making decisions in our organization.” We modified some items from the CHSRF tool by considering five stakeholder perspectives represented by the participants. For example, an item for practitioners and administrators that read, “We communicate internally in a way that ensures there is information exchanged across the entire organization,” was changed for parents to read, “We communicate with other parents in a way that ensures there is information exchanged as widely as possible.” Three assessment versions resulted: one for Parents, one for Researchers, and one for Administrators, Policymakers, and Practitioners. Participants rated each item on a 5-point Likert scale as follows: 1 = Strongly Disagree, 2 = Disagree, 3 = Neither Agree or Disagree, 4 = Agree, 5 = Strongly Agree.

The assessment results were tabulated and presented to the group immediately following the completion of the forms. The summary results informed all subsequent discussions at the workshop.

3. Identifying important contextual facilitating and impeding factors

Participants discussed their assessment results in groups in order to identify and prioritize facilitating and impeding factors for KT within their work, organizational, or family context. They were encouraged to discuss the factors that contributed to their three highest and three lowest average assessment ratings. They were prompted to consider: (a) the reasons for the high/low scores, (b) why KT is successful/unsuccessful in those areas, and (c) actions and resources that would be needed to generalize successes and/or address KT deficits in those areas.

4. Discussing future directions for developing KT processes and practices

Participants identified concrete ways that researchers and stakeholders in Manitoba could work together, and discussed how they could build upon the day's successes. Two specific questions were posed: (a) Where do we go from here? (b) What are the top priorities for a local KT initiative?

Workshop Evaluations

Participants in each workshop evaluated their session by rating nine items on a scale from 1 (Strongly Disagree) to 5 (Strongly Agree). They were also asked to provide an overall assessment of the workshop on a 5-point scale from 1 (Poor) to 5 (Excellent).

Results

Assessment Results

Table 1 displays section and subsection averages based on ratings from all 64 participants on items in the indicated ranges. A one-way repeated measures ANOVA based on the 56 participants who completed all four survey sections found a significant effect of survey section (Acquire, $M = 3.3$; Assess, $M = 3.3$; Adapt, $M = 2.8$; Apply, $M = 3.6$) on item ratings ($F_{(3, 53)} = 17.88, p < .001$). Pair-wise comparisons indicated that each section's mean rating was significantly different at the .05 level from every other section's mean rating, with the exception of the Acquire and Assess sections. The Apply section mean rating

was greater than the mean ratings of the Acquire section ($t_{(55)} = 2.759, p = .008$), the Assess section ($t_{(55)} = 2.226, p = 0.030$), and the Adapt section ($t_{(55)} = 7.225, p < .001$). The Adapt section mean rating was less than that of the Acquire section ($t_{(55)} = -5.146, p < .001$) and of the Assess section ($t_{(55)} = -4.952, p < .001$). The effect of survey section on item ratings within each stakeholder group generally followed the pattern of the overall sample, except that the Acquire section was lowest-rated for Parents ($M = 3.5$), and the Assess section was highest-rated for Practitioners ($M = 3.3$) and for Researchers ($M = 3.8$).

Some items prompted particularly high levels of agreement (i.e., ratings of 4 or 5) and low disagreement (i.e., ratings of 1 or 2) from participants. Notably, 76% agreed with item 22, "We value research," and only 7% disagreed. Seventy-one percent agreed with item 15, "Our staff can identify the relevant similarities and differences between what we do and what the research says," and only 6% disagreed. Sixty-four percent agreed with item 26, "We value and reward flexibility, change and continuous quality improvement," and only 16% disagreed.

Participants reacted to some other items with low agreement and relatively high disagreement. Only 22% percent agreed with item 18, "We have enough skilled staff with time, incentives, and resources who use research communication skills to link research results to key issues facing our decision makers," and 48% percent disagreed. Twenty-nine percent agreed with item 2, "Our staff has enough time for research," and 47% disagreed. Twenty-five percent agreed with item 16, "We have arrangements with external experts to identify the relevant similarities and differences between what we do and what the research says," and 33% disagreed.

Discussion of KT Facilitating and Impeding Factors

A total of 128 participant comments were recorded across the three workshops. The discussion of impeding factors produced over twice as many comments (91 of 128) as did the discussion of facilitating factors (37 of 128). To analyze this content, we coded each comment with one or more keywords relating to the comment's topic or theme.

Table 1. Average Ratings by Assessment Subsection

| Subsection | No. of Items | All | ADM ^a | PAR ^b | PRC ^c | RES ^d |
|--|--------------|-----|------------------|------------------|------------------|------------------|
| n | | 64 | 16 | 10 | 17 | 21 |
| Section 1: Acquire | | | | | | |
| Are we able to acquire research? | 5 | 3.1 | 2.7 | 3.4 | 2.9 | 3.5 |
| Are we looking for research in the right places? | 7 | 3.5 | 3.2 | 3.6 | 3.3 | 3.7 |
| Acquire section combined averages | 12 | 3.3 | 3.0 | 3.5 | 3.1 | 3.7 |
| Section 2: Assess | | | | | | |
| Can we tell if the research is valid and of high quality? | 2 | 3.3 | 2.8 | 3.1 | 3.1 | 3.9 |
| Can we tell if the research is relevant and applicable? | 2 | 3.3 | 2.8 | 3.6 | 3.4 | 3.7 |
| Assess section combined averages | 4 | 3.3 | 2.8 | 3.7 | 3.3 | 3.8 |
| Section 3: Adapt | | | | | | |
| Can we summarize results in a user-friendly way? | 4 | 2.8 | 2.4 | 3.6 | 2.7 | 3.0 |
| Section 4: Apply | | | | | | |
| Do we lead by example and show how we value research use? | 7 | 3.6 | 3.4 | 4.1 | 3.1 | 3.7 |
| ^a Administrators and Policy-Makers ^b Parents ^c Practitioners ^d Researchers. Rating scale from 1 (lowest) to 5 (highest). | | | | | | |

Facilitating factors. Topics that recurred most frequently during the discussion of facilitating factors included the critical role of clinicians and practitioners in the knowledge translation process. For example, “clinicians know more about the resources that are available (e.g., journals)” than do many parents or front-line staff. Although this expertise facilitates KT, it requires time and effort to maintain. We heard that, “clinicians need to practice in areas of expertise and recognize [their] limitations in order to bring competency levels up.”

Peers were seen as another important source of knowledge. We heard that, “peer networking is successful because it is efficient” and that peers are often a “...more relevant source because they are able to provide concrete examples.” Peer networking was seen as especially important by parents, who emphasized that KT processes must meet the needs of, “...two types

of parents: 1) those belonging to groups, associations, and 2) individual parents who are not part of a larger group.”

Attendees affirmed that they value research and noted the breadth of its application. We heard, for example, that direct care providers, “...want to give the best possible care,” while administrators, “...recognize and value how research can play a role in the development and shaping of policies.” Both parents and practitioners recognized that DD is a lifelong condition. Thus, research is important, “in early, years, for diagnosis,” and “in middle/late years, for deciding on best practices and education.”

Impeding factors. Topics that recurred most frequently during the discussion of impeding factors included research accessibility. Knowledge users need physical access to information, and they need to find it in appropriate

language. For example, we heard that research should be, "...presented at conferences that we can access," and, "...available online, everything published should be freely accessible," and not solely, "...in journals which are difficult to get a hold of." Furthermore, abstracts should, "be written in plain language so we can see if it's relevant," because, "language usage is sometimes way above our understanding."

Finding the time to stay abreast of research findings was recognized as a major challenge, and this concern was often related to staffing. We heard that, "with reduced staffing, there are fewer people doing more things and this leaves little time for research." Similarly, "Working in a hospital you are dealing with the moment and you just don't have time to be proactive—you are reacting."

Many participants suggested that improved KT must start with organizational support. For example, "Job descriptions/expectations need to include research as a priority." One participant wished to see a situation where, "using best practices is an operational policy, organization is committed to it and they support that policy by providing resources." Another saw the key as, "having an organizational culture that values continued learning." A dedicated research coordinator position and/or research liaison were also proposed. The theme of collaboration recurred: it was suggested that organizations should invite researchers to sit on their board committees, and that the connection between academic research and field training programs be strengthened.

Recommendations and Future Directions

Future meetings were encouraged, and it was suggested that we formalize a structure for an ongoing KT initiative. We were advised to hold meetings that: (a) build cumulatively on the output of previous meetings; (b) are organized around the CIHR KT model; and (c) address different types of research activity, including program evaluation, basic science, and library research. Semi-annual KT conferences were suggested, as was a KT stream of presentations at the annual St. Amant Conference on Developmental/Intellectual Disabilities and

Autism. It was also suggested that we produce a concrete KT mechanism, such as a telephone information line or website that would be accessible for parents.

Session Evaluations

The overall mean rating of the three workshops was 4.2, equivalent to a rating of Very Good. Workshop participants had the opportunity to further comment on the evaluation form. The most recurrent theme in the written comments was appreciation for the chance for participants to learn from each other. One participant wrote: "I think any opportunity to connect with people who work/research in the field is invaluable." Another participant wrote, "Great opportunity to learn more from the various perspectives of stakeholders." One participant indicated prior familiarity with KT concepts, yet wrote, "I work within [these concepts] now so I did not learn any new theory—I learned from the experts in the field and from other stakeholders (parents)."

Discussion

Our objectives were to: (a) strengthen partnership and commitment for KT in DD, and (b) learn from stakeholders about research priorities and contextual factors that facilitate and impede KT. Both objectives were achieved. Participants found the workshops to be "Very Good" overall and appreciated the opportunity to network with other stakeholders. The St. Amant Research team was encouraged to plan and organize subsequent KT activities, and many participants indicated willingness for continued involvement.

We asked participants to self-classify themselves into one of the four groups of parents, practitioners, policy makers and administrators, and researchers. This allowed us to hear different perspectives and find out more about factors that facilitate or impede KT for DD for these different groups. For future KT activities, we were encouraged to engage a larger number of parents from the community (especially those who are not connected with a group or association) as well as representatives from medicine, genetics, and child health specialists.

Participants from all of the stakeholder groups highly valued research, and there was special interest in research that can answer questions at field and policy levels, not just at academic levels. Researchers and decision-makers should therefore collaborate to formulate appropriate research questions and to conduct the research, as suggested by the CIHR KT model. This collaborative research could lead to the creation of useful knowledge, but researchers reported publishing most often in academic journals, and were encouraged to find and use more accessible knowledge dissemination channels for their research findings.

The discussion content, as measured by frequency of keywords, was generally consistent with the highest-rated and lowest-rated items from the KT capacity assessment. A possible exception was the item, "Our staff can identify the relevant similarities and differences between what we do and what the research says," with which 71% agreed and only 6% disagreed. These scores could mean that staff are well-aware of best practices based on research evidence, and are also aware of the extent to which they follow the practices. However, the item occurs in a subsection titled, "Can we tell if the research is relevant and applicable?" It is therefore plausible that staff agreed highly with the item because the research information that they encounter is often irrelevant to their daily practices. Future applications of the KT capacity assessment tool could be adjusted to probe this ambiguity.

Participants indicated that current policies and practices of their organizations often do not adequately support staff or administrators to get involved in research. Developing effective KT partnership therefore requires revising organizational mission statements, policies, and job descriptions to reflect research as a priority. These findings are consistent with those of other researchers in the KT field. Specifically, barriers such as lack of time, resources, expertise and organizational support for research uptake have been previously identified in the field of social work (Sheldon & Chilvers, 2000), nursing (Funk, Tornquist, & Champagne, 1995), school psychology (Kratochwill & Shernoff, 2004), and children's mental health services (Hoagwood, Burns, Kiser, Ringeisen, & Shoenwald, 2001).

Facilitating and impeding factors for KT in DD appear to be much the same as those from other fields. A logical next step would be to design, implement, and evaluate a KT process or mechanism, as requested by several of our participants. A series of such efforts may foster a technology of KT for the benefit of all stakeholders (Graham & Tetroe, 2007; Straus, Tetroe, & Graham, 2009), and ultimately, persons with DD.

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