

# Research Center Takes New Approach to Knowledge Translation: Building Bridges from Research to Policy and Practice



## **Executive Summary**

- Research can more effectively improve the lives of people with disabilities and older adults when researchers, practitioners and policymakers share information and goals early in the research process.
- The Research and Training Center on Community Living held an innovative "Bridging Meeting" in April 2013 to establish connections among its research partners, representatives of national policymaking agencies and independent living experts.
- This meeting represents an integrated approach to knowledge translation by involving stakeholders and knowledge users in the early stages of the five-year project rather than relying on end-of-grant communication alone.
- Through a rapid delivery process, we presented information about the Center's 11 projects in one day to begin exploring useful connections with our stakeholders and knowledge users.

RESEARCH CAN MORE EFFECTIVELY IMPROVE THE LIVES of people with disabilities and older adults when researchers, practitioners and policymakers share information and goals early in the research process. To build these connections, the Research and Training Center on Community Living (RTC/CL) hosted a "Bridging Meeting" on April 16-17, 2013 in Alexandria, Va.

This innovative knowledge translation (KT) event brought together internal and external stakeholders and knowledge users midway through the second year of the five-year project to demonstrate the Center's commitment to KT as a continuous process, rather than just a summative activity when the work concludes.

The meeting gathered the Center's research partners, members of its Scientific and Consumer Advisory Panel (SCAP), national policymakers and independent living experts to explore ways that the Center's research on community living and participation can influence both practice and policy to benefit people with disabilities and older adults. Representatives of the following national organizations attended the Bridging Meeting:

- National Institute on Disability and Rehabilitation Research
- Administration on Community Living
- Centers for Disease Control and Prevention
- National Council on Independent Living
- Association of Programs for Rural Independent Living

## **Emphasis on Process: Building Bridges**

Researchers typically wait until their work on a given project is complete to report the results in peer-reviewed journals and at professional conferences, making the results available for others to use in practice, policy or their own research. However, sometimes the distribution of research results never reaches beyond professional journals and conferences, leaving other stakeholders unaware of important and timely research findings.

Rather than relying on end-of-grant KT alone, we are taking an integrated approach to knowledge translation in the Center by involving knowledge users throughout the five-year research project. In this integrated KT (iKT) approach, potential knowledge users are engaged throughout the process in order to produce results that are more likely to be relevant to and used by end users (Bowen & Graham, 2013). Engaging people who want and need your information early in the process can add important perspectives to the research process as well as to ongoing KT plans (CIHR, 2012).

We chose the bridge as a metaphor for this meeting because we had two goals that both involved building connections. First, we wanted to reach out to selected stakeholders and knowledge users to establish relationships between our Center and their organizations. Our researchers routinely incorporate consumer-empowered teams into their research designs, involving consumers as collaborators (White et al., 2002). In addition, we knew that this Center could both benefit and benefit *from* other individuals who represent policymaking agencies and consumer organizations.

Second, we wanted to explore more fully the relationships among the separate research projects within the center, especially the connections between the eight secondary data analysis projects that were conducted in the first year of the Center and the five

intervention development projects that launched in year two. While our research partners share their progress with each other in monthly teleconferences, we felt a face-to-face meeting combined with the perspectives of other stakeholders would enable us to discover additional ways that the secondary data projects could inform the interventions.

Despite the caveats about presenting research while it is in process, there are several benefits of sharing of research at this point. This approach (a) informs stakeholders in a timely way about evidence that has potential use for their own missions; (b) enables policymakers to identify policy implications in the research; (c) helps researchers build relationships with individuals and organizations who may contribute important insights, strategies and even resources to the evolution of a project; and (d) increases the likelihood that, going beyond references in journal articles, the research will actually be used in practice and policy. These interactions may inform adjustment in the research at an early stage while maintaining the integrity of the original research design.

# The Opportunity: Why We Need to Talk Early and Often

The meeting was facilitated by Ian Graham, PhD, FCAHS, an internationally known KT expert, who led the meeting as a "Best Brains Exchange." Dr. Graham facilitates these exchanges as an opportunity to (1) provide policymakers with an overview of the best evidence available on an issue and timely advice from researchers, and (2) provide researchers with policymakers' perspectives on their research and findings.

Graham is Senior Scientist at the Centre for Practice-Changing Research, the Ottawa Hospital Research Institute, and Professor in the School of Nursing at the University of Ottawa, Ontario, Canada.

Graham notes that researchers and decision-makers in both the policy and practice arenas use and value different knowledge systems. Researchers must recognize these differences in order to communicate effectively for the benefit of the public – in this case, people with disabilities and older adults.

Decision makers'	Researchers'
Evidence	Evidence
<ul> <li>Colloquial</li> <li>Anything that seems reasonable</li> <li>Context specific</li> <li>Policy relevant</li> <li>Timely</li> <li>Clear message</li> </ul>	<ul> <li>Scientific</li> <li>Proven empirically</li> <li>Theoretically driven</li> <li>Generalizable</li> <li>As long as it takes</li> <li>Caveats and qualifications</li> </ul>

A U.S. study of 292 state health policymakers (Sorian & Baugh, 2002) showed that the following factors are related to research usefulness: the research is timely and relevant to political debates; the presentation of the research is brief (short reports or summaries); the researcher identifies policy implications/recommendations; and the researcher limits statements to the actual findings.

In addition to understanding the interests and communication styles of decision makers, these factors also influence the use of research evidence:

- Interactions between researchers and policymakers in the context of policy networks (e.g., formal advisory committees, informal relationships)
- Research that matches the beliefs, values, interests or political goals and strategies of elected officials, social interest groups, others (Lavis et al, 2005)

# Six-Minutes or Less: How the Bridging Meeting Worked

The Bridging Meeting followed Graham's format for a "Best Brains Exchange." In a one-day, closed door meeting, Center researchers, advisory members, policymakers and independent living (IL) practitioners discussed a government-identified, high-priority issue: community living for people with disabilities and people who are aging. The RTC/CL researchers summarized the relevant evidence and suggested the implications for possible policy directions.

To present their evidence, the researchers adapted a Japanese technique known as Pecha Kucha, which keeps presentations concise and fast-paced for multiple-

speaker events. Each researcher had six minutes to present six slides, which included a summary of their findings and potential implications for consumers, IL practitioners and policymakers. Each short report was then followed by nine minutes of discussion, with questions and answers from the policymakers and other stakeholders.

This rapid presentation technique enabled the meeting participants to learn about the findings of eight secondary data analysis projects, which were at or near completion, and the launch of five intervention development projects that are testing new ways to enhance community living. The day ended with observations from the policymakers and a general group discussion.

The second day of the Bridging Meeting was an opportunity for a more intimate, "insider" briefing. The researchers, advisory panel members and IL experts met without the policymakers to discuss their feedback and continue exploring ideas on how to adapt this research or make it more accessible for both practice and policy.

# Six Minutes, Six Slides

We asked researchers to distill the essence of their findings for the Bridging Meeting participants. In this rapid presentation format, they:

- Summarized the findings of a secondary data analysis project or outlined their plans for an intervention project
- Stated the implications for consumers, practitioners and policymakers

The Center provided researchers with a PowerPoint template that helped them structure their presentations and added continuity to the day.

The process used to stage this meeting is outlined in "Building the Infrastructure: Hosting a Bridging Meeting."

#### **The Outcomes**

This meeting yielded a number of positive outcomes to better inform disability policy and practice. These outcomes include:

- RTC/CL researchers established linkages with policymakers, creating common ground.
- Policymakers indicated an interest in collaborating on certain projects and suggested how to accomplish that collaboration.
- Attendees provided names of other consumer groups, policymakers and agencies who could inform and benefit from the continuing discussion.
  - o *Example:* Charlie Lakin, Director of the National Institute on Disability and Rehabilitation Research (NIDRR), worked with researcher Craig Ravesloot after the meeting to submit a one-page brief to the department of Housing and Urban Development (HUD). The brief summarized Ravesloot's findings on "The American Housing Survey and Disability."
- Participants suggested modifications for some of the intervention projects. Based on the input received, researchers made revisions to increase the effectiveness and relevance of several projects.
  - o *Example:* We revised the purpose, scope and title of R-7, which was originally titled Health Navigator Training. See "Next Steps" below for more information.
  - o *Example:* Access to health care was added to R-10, the Community Engagement Initiative Knowledge Transfer Project.

Attendees appreciated the concept of the Bridging Meeting as well as its format. In the meeting evaluations, they named these aspects of the event as "most liked":

- Opportunity to network and think about effective strategies.
- Loved the rapid data format.
- The agency partners and consumer panel in the same room was cool.
- I found the fast pace engaging and informative.
- Focused presentations and discussion.
- The overall format (6 minute presentations).
- Opportunity to hear about and comment on developing research and interventions.
- Feedback from the field

- Good representation of researchers and policymakers opportunities to interact with all participants.
- We all need to practice this multi-sector collaboration.

The researchers, advisory panel members and IL experts identified the following benefits during the second day of the meeting, when the policymakers were not present:

- Honest and open dialogue about RTC projects. Ample amount of time for processing.
- Interaction the varying perspectives. Folks' willingness to share their ideas.
- It was great to pull together so many informed and passionate folks to engage in interesting and relevant conversations.
- Informed discussion of issues that affect many projects; opportunities to get guidance from stakeholders.
- In-depth dialogue. Multiple perspectives.
- I enjoyed the conversations about RTC and evidence-based research in communities as well as the advice on how to ID and reach a variety of potential audiences with KT.
- The openness and richness of the discussion.
- Thinking about connections across projects
- Thinking about ways to improve quality of the studies.

# **Finding Connections, Sharing Goals**

As a NIDRR-funded grantee, the RTC/CL projects all respond to NIDRR's priorities for enhancing community participation of people with disabilities. With the creation of the Administration for Community Living (ACL) in 2012, we are identifying the natural connections between our work and the plans and objectives of this comprehensive federal agency (see chart on pages 5-7). The Bridging Meeting represents the first formal step across that bridge to integrate our work with theirs in order to meet the needs of a larger community that includes both older adults and people with disabilities.

The following items indicate areas where our Center's work can enhance and support specific goals and objectives within the ACL's Strategic Plan.

# How the RTC on Community Living Contributes to the Administration for Community Living's Goals

The ACL Strategic Plan 2013-2018 (2013) outlines five strategic goals. The RTC/CL contributes to the following ACL goals and objectives through a number of its projects.

#### ACL Goal 3 - Individual Self Determination and Control

Objective 3.3. Increase the availability of promising and evidence-based programs and practices that empower individuals to improve the quality of their health, independence and well-being.

#### **How the RTC/CL contributes:**

- Housing and transportation (independence): Two projects address the fact that the availability of
  accessible and affordable housing presents a key barrier for individuals who want to move out of
  institutional care.
  - R-1, Housing and Transportation Access, a secondary data analysis project, has identified
    the proportion and demographic characteristics of people with disabilities who experience
    significant housing barriers.
  - o *R-9, Fair Housing Compliance Assessment and Advocacy,* an intervention, develops new advocacy methods and measures that centers for independent living (CILs) and other advocates can use to enhance the accessible housing stock in their area by monitoring compliance with and advocating for adherence to federal housing laws.
- Health and well-being: Three projects focus on this important area.
  - The impact of chronic health conditions on people in several disability subgroups is described in R-4, Multiple Chronic Conditions and Healthcare Access, a secondary data analysis.
  - SSR-2, Updating a Systematic Scoping Review of the Literature on Healthcare Use and Receipt of Clinical Preventive Services by People with Disabilities identifies gaps in the research literature regarding how persons with disabilities use clinical preventive services.
  - R-7, Developing a Health Promotion Assistance Tool (formerly called Health Navigator Training) builds on the above findings about clinical preventive services. This intervention development project will provide tools for CIL and ADRC staff to support proactive health management and, in so doing, help ensure continuity of community living and community participation. (The name and design of this project have been revised; see "Next Steps" below for more information).
- **Self-directed care (independence):** Intervention *R-8, Development and Testing of an Informal PA Training Program* will develop, implement and test a training program for providers and consumers of informal (unpaid) personal assistance (e.g., family members and friends). The goal is to improve the knowledge and skills of informal care providers and the consumers they assist in order to avoid disruptions in community living and to enhance community participation.

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• Institutionalization (independence): SSR-1, A Systematic Scoping Review of the Literature on Risks for Institutionalization of People with Disabilities assesses the research literature and identifies gaps in it regarding factors that are associated with institutionalization and barriers to remaining in the community for people with disabilities ages 18-65.

ACL Goal 3 – Individual Self Determination and Control
Objective 3.4. Promote and increase the accessibility of all aspects of community life.

#### **How the RTC/CL contributes:**

- **Community and civic engagement:** The intervention *R-11, Building Capacity for Full Community Participation* expands the ability of CIL staff to help their consumers engage more fully in civic life. The study is testing how the strategy of creating community and systems change enhances community participation for people with disabilities in a variety of areas, including volunteering, education, civic engagement, etc. This intervention, like the others, runs through 2016.
- **Recreation:** Intervention *R-10, Community Engagement Initiative (CEI) Knowledge Transfer (KT) Project* applies a grassroots community engagement technique to assess the efficacy of the method for enhancing access to recreation. This technique has been successfully used to enhance access to health care; the focus on recreation will test effective knowledge transfer methods for using the CEI.

#### **ACL Goal 4 – Long-Term Services and Supports**

Objective 4.4. Promote the development and adoption of national standards for home and community-based services, including quality standards that reflect consumer experience with long-term services and supports programs.

#### **How the RTC/CL contributes:**

- **Support for removing barriers:** These intervention projects will develop processes and programs to remove or ameliorate barriers. (See descriptions above.)
  - o R-7, Developing a Health Promotion Assistance Tool (formerly called Health Navigator Training)
  - o R-8, Development and Testing of an Informal PA Training Program
  - o R-11, Building Capacity for Full Community Participation

#### Understanding the need:

- SSR-1, A Systematic Scoping Review of the Literature on Risks for Institutionalization of People with Disabilities provides insight into research gaps related to removing barriers to community living.
- R-6, Personal and Environmental Factors Influencing Community Living for People with
   Disabilities analyzes data that explores the relationships between community participation and
   environmental facilitators, as well as person (demographic), health-related, geographic and
   impairment factors.

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In addition to the other goals supported by the RTC on Community Living, our parent center contributes to meeting the ACL's advocacy goal through a well-known product.

#### ACL Goal 1 - Advocacy

Objective 1.1. Increase public awareness and understanding of the interests of people with disabilities, older adults, and their family members.

#### How the RTC/CL contributes:

• Media Portrayal: The Research and Training Center on Independent Living produces a disability language resource to increase awareness and understanding of people with disabilities. *Guidelines: How to Write and Report About People with Disabilities* (8<sup>th</sup> edition) recommends objective terminology for discussing people with disabilities and chronic health conditions. *The Associated Press Stylebook, the Publication Manual of the American Psychological Association* (6<sup>th</sup> edition) and the American Association for the Advancement of Science have all adopted some of the *Guidelines'* recommendations. Since the first edition was published in 1984, more than one million copies of the brochure have been distributed and the electronic version is used by people around the world. A companion poster, "Your Words, Our Image," is also widely used in a variety of fields, including health care.

## **Putting It on Paper: Sample KT Products**

To supplement the meeting discussions, we provided materials produced by the Center that present the early findings, as well as related publications from our previous center, the Research and Training Center on Measurement and Interdependence in Community Living (MICL). These materials illustrate different methods of communicating with different target audiences.

### Plain language publications for all audiences:

Fact sheet and Infographic: Multiple Chronic Conditions Among People with Disabilities Fact sheet: How Do Vocational Rehabilitation Outcomes Vary Among Different Types of Living Arrangements?
Fact sheet: Building Capacity for Full

Community Participation

Fact Sheet: Using a Community Engagement Process to Improve Health Care Access

# Publications for advocates, health care providers and policymakers:

Brochure: Disability Resources for Health Care Providers: How to Make Your Medical Practice More Accessible to People with Disabilities White Paper: Improving Access to Health Care for Kansans with Intellectual and Developmental Disabilities: A White Paper

# Publications for researchers:

Poster presentation: Multiple Chronic Conditions and Health Disparities among People with Disabilities Compared to People without Disabilities

Journal article: "Using population-based data to examine preventive services by disability type among dually eligible (Medicare/Medicaid) adults." Disability and Health Journal.

Journal article: "The Oregon Community Engagement Initiative: A Multi-Case Study of a Disability Coalition Development Process." Community Development.

#### Training tools for practitioners:

Assessment tool for health care facilities:
Outpatient Health Care Usability Profile V4
Online Documentation Support System: A
tool for capacity building provided by the
Community Tool Box

# **Next Steps: Continuing the Conversation**

A bridge connects two shores or spans an obstacle in the pathway. It is built to be used, to be travelled in both directions, and sometimes to provide a meeting place in the middle. The Bridging Meeting was the Center's first constructive activity to involve additional stakeholders who can assist in achieving our goal: Translating this research into policy and practice for the benefit of people with disabilities and older adults.

At the time of this writing, Center researchers have had an additional six months since the meeting to continue the intervention development process and to analyze their secondary data findings. They are incorporating feedback from the meeting to refine their projects and create messages about their progress to date.

The meeting prompted a major adjustment for one project. We revised the purpose and scope of R-7, which was originally titled Health Navigator Training. Now called Developing a Health Promotion Assistance Tool (which avoids confusion with Affordable Care Act navigators), this intervention will develop a database that will enable CIL and Aging and Disability Resource Center (ADRC) staff to get targeted information for consumers and develop short-term health promotion plans with them. The inclusion of ADRC specialists in the development and testing of the strategy was in part a result of the Bridging Meeting.

Having established contact and communication among all the participants, we intend to continue fostering the dialogue that began at the meeting in Alexandria. As KT expert Peter Levesque notes (2013), in measuring the impact of knowledge translation efforts, we should recognize that while "content is king ... conversation is queen." During the time that the Center's content (data analysis and intervention development) is still being developed, we will facilitate continued conversations through phone calls, teleconferences, emails and face-to-face meetings when possible.

At the end of the Bridging Meeting, we asked the participants to indicate projects on which they would like to collaborate and how that collaboration could occur. We are using those suggestions by connecting the appropriate individuals. Participants also suggested other stakeholders (consumer groups, policymakers and agencies) who could inform this discussion about improving community living and participation for people with disabilities, whom we are contacting.

As the demographics of U.S. society change and as people with disabilities and those who are aging continue their quest to live in and fully participate in their communities, we are committed to conducting relevant, timely and rigorous research to support those

goals. We are also committed to finding innovative ways to span the traditional gulfs between researchers, policymakers and practitioners, to ensure that our results have the best possible opportunity to be applied and to benefit people's lives.

#### References

ACL Strategic Plan 2013-2018. (2013). Retrieved on Oct. 15, 2013, from http://www.acl.gov/About\_ACL/StrategicPlan/docs/ACL Strategic Plan.pdf.

Bowen S., and Graham I.D. (2013). "Integrated knowledge translation." In S.E. Straus, J. Tetroe & I.D. Graham (Eds.), *Knowledge Translation in Health Care. Moving From Evidence to Practice* (pp. 14-23). Oxford: Wiley-Blackwell.

Canadian Institutes of Health Research (CIHR). (2012). Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches. Retrieved Oct. 15, 2013 from http://www.cihr-irsc.gc.ca/e/45321.html#a3.

Lavis, J.N., Davies, H.T.O., Oxman, A.D., Denis J.L., Golden-Biddle, K., Ferlie, E. (2005). Towards systematic reviews that inform health care management and policymaking. *Journal of Health Services Research and Policy*. 10(S1):S35–S48.

Levesque, P. (October 2013). "Measuring for Impact." Presentation in online conference *Knowledge Translation Measurement: Concepts, Strategies and Tools*. Retrieved on Nov. 4, 2013 from http://www.ktdrr.org/conference/expo/conf\_materials.html.

Sorian, R. and Baugh, T. (2002). Power Of Information: Closing The Gap Between Research And Policy, *Health Affairs*, 21: 2, 264-273.

White, G.W., Nary, D.E., Froehlich, A.K. (2001). Consumers as Collaborators in Research and Action. *Journal of Prevention & Intervention in the Community*. 21:2, 15-34.

#### For More Information

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