

Disseminating Disability Research to Policymakers

Think Tank Recommendations

September 2006

Statement of Need

While the goal of disability and biomedical research is to improve the public's health, there is no consistent system to translate research findings into public policy. Without widespread application through public policy, even the most important research will have little effect. It is not well understood why this disconnection between research and policy exists, though one researcher found that a "clash of cultures" was a significant factor (Brownson, 2006). It is imperative that researchers find ways to bridge the gap between research and policy by working directly with policymakers to translate their research for policy implementation.

Methods/Strategy

Seven experts in the fields of disability research, disability advocacy, and policymaking were invited to participate in a three-hour brainstorming session, or "Think Tank," sponsored by the RRTC: Health & Wellness, held in conjunction with the RRTC on Aging with a Disability's State of the Science Conference on September 7, 2006. The goal of the Think Tank was to generate recommendations to increase the likelihood that research findings are used in policymaking. In this dialogue, we hoped participants would speak candidly about the "culture clash" between researchers and policymakers and discuss strategies to overcome it.

Five key questions were posed to the Think Tank participants a week before the meeting and framed the discussion:

- We presume that researchers want their findings to influence policy, and that policymakers want research to support policy. When and to what extent are those presumptions accurate?
- Why doesn't this happen more? What can we do to support it?
- What are the processes of developing policy and where could research findings be useful?
- What can researchers do to have their findings influence policy more?
- What is the *most important* thing that researchers can do to influence policy?

Gloria Krahn, Director of the RRTC: Health & Wellness facilitated the process of structured dialogue that ensured each participant had the opportunity to contribute

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unique ideas or perspective to the questions. A different participant led off on each new question in order to give everyone a chance to speak. RRTC recorded the proceedings. Due to the nature of this discourse, few direct answers to the proposed questions were posed. Instead, several themes emerged from the dialogue that are organized into sets of recommendations.

Recommendations for Researchers

Master the policy process

The experts agreed that the most important thing a researcher can do to influence policy is simply to be interested in influencing policy. While legislators are likely to be interested in research, it seems that researchers are generally less interested in informing policy. Researchers who want their findings to influence policy must learn to successfully navigate the policy process. There are several steps to achieving this, beginning with knowing the legislators involved. Also, know legislators' committee assignments and the importance of committees in the legislative process. Build relationships with legislative staffers, who often have fewer turnovers than legislators themselves. Recognize that each administration has a distinct culture in terms of how much influence is available through formal or informal means. Learn to anticipate the changing political climate and position yourself accordingly. Know that even the most expertly conceived policy might look different under the influence of limited budgets and regional interpretation. Understand how the three branches of government operate and interact. For example, the Legislative Branch has more time and flexibility to consider research findings. They are responsive to their constituents and are always working on the "next vote." The Judicial Branch is more motivated by evidence and precedence and is responsive to legal suits. The Executive Branch must make concrete and implementable decisions and often has to follow judicial or legislative directives with a limited budget. Data should be tailored to respond to the needs of the particular branch of government being approached. Lastly, the researcher's and the policymaker's role and context must be understood. The policymaker is the expert in the policymaking process and the researcher must respect that expertise and be willing to allow the policymaker to take the lead. In fact, one participant stated, "researchers need to humble themselves to the policy process" to emphasize this point.

Research available funding streams

One of the biggest hurdles to performing policy research is securing funding. The researcher must be aware that there are funding streams available for systems-based research (e.g., Centers for Medicare and Medicaid Services). By favorably positioning him/herself in the policy sphere, the researcher gains access to information about available funding that might not otherwise be known. Also, existing funds can be tapped by couching researcher interests in terms of contemporary issues. For example, if the proposed research is to study physician behavior and cancer research is currently getting funded, the study should propose to study physician behavior with cancer

patients. It may also be possible to bundle funding across multiple states while researching a particular issue. There may be regional similarities or demographic similarities across states. Researchers must learn to ask themselves what policy research questions can be answered that will make a difference and design their studies accordingly.

Cultivate trust-based relationships

Building trust-based relationships with policymakers is critical to ensuring that research findings will be used for making policy decisions. Policymakers are besieged with special interests and must determine quickly who has credible information. Building a reputation for impartiality and transparency will increase the chance that a policymaker will not only listen to this issue, but also seek the researcher out for information on the next issue. Researchers should disclose all biases and conflicts of interest at the outset to avoid being considered a front for corporate entities. It is crucial not to overstate research findings to influence policy- overstating findings threatens present and future credibility. At the same time, provide answers that are clear and simple to the best of your knowledge- save caveats about the findings for follow-up questions and then maintain a non-defensive stand. Make research processes transparent and be prepared to back the findings even if they do not show the hoped-for results. Developing a reputation for credibility will grant access across all branches of government and with industry.

Build Alliances

There is a potential for powerful coalitions between researchers and disability organizations. However, these alliances should be formed with care and purpose. Disability organizations have a great deal of political power. They drive the disability-policy agenda, have an investment in the policy process and have an increasing interest in research. Working with these organizations on particular research questions can increase the likelihood of research findings being used. Because of the nature of advocacy groups, however, policymakers may feel that research that is advocacy based is biased and has less credibility than research conducted by a neutral party. Many disability advocacy organizations are forming a research arm in order to increase policy-directed research. Another strategy is forming relationships with foundations that fund research. They can lend credibility to the work and provide networking opportunities for future projects. There was general agreement that politics should not be used to do the work of research: if the issue is evidence, do not engage in such political tactics as using a room full of people in wheelchairs to force a vote on a policy issue. While it might be successful for that vote, power in influencing the *next* vote will be jeopardized.

Synthesize research

Synthesis is becoming increasingly important to policymakers as they rely on scientific data to make policy decisions. There are multiple forms of research synthesis and

researchers should be proficient in all of them. Recognize the importance of systematic reviews, which allow a researcher to synthesize all the studies addressing a question when presenting data to policymakers. This step gives them the “state of the science” in one document and bolsters the researcher’s credibility as the data is presented in context.

Create accessible reports

The presentation of research outcomes is as important as the data itself. Use plain language that speaks to the context of the policymaker. Limit reports to what is timely and relevant. In the past, personal stories were used to raise awareness; however, policymakers are now more interested in data. If “poster children” are used, be sure to provide the relevant data. Instead of over-qualifying data, explain it with point estimates. Policymakers are generally not interested in confidence intervals, though if questioned, the researcher should be able to delve into the more technical aspects of statistical analysis. Most importantly, understand that policymakers operate under timelines that do not usually coincide with the research process. Make every effort to know the timeframe (e.g., a vote this afternoon vs. a committee meeting in one month) and present your findings appropriately. Keep the report simple—use a one-page fact sheet rather than a lengthy report; place details in an appendix if necessary.

Develop opportunities and training for policy-research careers

Even if researchers are interested in influencing policy, there are few professional incentives for them to do so. Systems-based change is needed to encourage more researchers to participate in policy research. There is a need for a career track that facilitates policy-based research. The current emphasis on translational research is a valuable example. One strategy is to build understanding of policy processes in the training of all disability researchers and healthcare practitioners. Policy field placements for researchers early in their careers could influence researchers to think from a policy perspective. Promotion and tenure guidelines need to be changed to build incentives for academic careers in disability policy that recognize the value of technical reports.

Conclusion Statement

Recommendations were generated based on five basic principles:

- transparency
- relevance
- accessibility
- credibility
- timeliness

Each of the preceding recommendations falls under at least one if not more of those five principles. By simply being interested in translating research into policy and adhering to the five principles when working with policymakers, researchers can

significantly advance the likelihood that their research findings will be used in policy decisions intended to influence the public's health.

Brownson, R. C. et al, (2006) Researchers and Policymakers: Travelers in parallel universes. *Am J Prev Med*; 30(2):164-172

Participants:

Roberta Carlin, JD, MA, MS

Roberta Carlin is the Executive Director of the American Association on Health and Disability in Rockville, MD. Ms. Carlin has over 25 years of non-profit management and program experience in disability issues. She has in-depth knowledge of federal legislative policy, grassroots advocacy, primary and secondary prevention programs, and information and program services. Ms. Carlin received her Juris Doctorate in 1991 from John F. Kennedy School of Law.

Richard Devylder

In August of 2003, the Governor of California appointed Richard to the position of Deputy Director for Independent Living and External Affairs at the California Department of Rehabilitation (DOR). He is the former Chairman of the State Independent Living Council (SILC) and Executive Director of Dayle McIntosh Center (DMC) based in Orange County. Mr. Devylder has extensive experience advocating for people with disabilities at the local, state and federal levels.

Jack Dempsey, BA

Jack Dempsey has almost a decade of experience working as a legislative staffer in state legislative politics. For the past four years, he served as the Legislative Director for the Oregon Senate President's Office. Prior to that, he was a policy analyst in the Senate Democratic Office. He recently joined the Office of Government and Community Relations at Oregon Health & Science University.

Rep. Mitch Greenlick, PhD, MS

Mitch Greenlick was the former director of the Kaiser Permanente Center for Health Research for more than 30 years, and directed an extensive program of health research that influenced policy. He is Professor Emeritus and past Chairman of the Department of Public Health and Preventive Medicine at Oregon Health & Science University. He now serves as a Representative to the Oregon State House of Representatives.

Gloria L. Krahn, PhD, MPH

Gloria Krahn is Director of the Oregon Institute on Disability & Development at Oregon Health & Science University. She is a clinical psychologist with training in public health who coordinates all research of the RRTC: Health & Wellness. She has been involved in disability research for more than 20 years.

Andrew Morris, MPH

Andrew Morris has seven years of health policy experience gained through working at the Oregon State Legislature, the Association of University Centers on Disabilities in Washington, DC, and in the Office of Government and Community Relations at Oregon Health & Science University. He graduated from Portland State University with a Masters degree in Public Health.

John Santa, MD, MPH

John Santa works with the Center for Evidence-based Practice at the Portland Veterans Affairs Hospital. Dr. Santa has experience working in state government as well as the insurance industry. He previously served as the medical director for the Drug Effectiveness Review Project.

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Contact Information:

RRTC: Health & Wellness

707 SW Gaines Street

Portland, OR 97239

(voice) 503-494-3534

7-1-1 Relay Service

(fax) 503-494-6868

rrtc@ohsu.edu

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