Research, Advocacy, and the Making of Public Policy

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The making of public policy is often likened to the making of sausage—people are advised not to watch it. Public policy is a complicated, chaotic mix of society's ethics, values, deeply held beliefs, and to a lesser extent, actual fact.

The making of disability policy is particularly complex because it incorporates social views, knowledge as well as misconceptions about how people become disabled, and the issue of societal responsibility for their well-being. Over time, research has supplanted many of the myths and unfounded beliefs about disability with empirical evidence about the cause, likely course, and probable impact of a wide range of chronic conditions and disabilities. But policy makers are first attuned to the perspectives of people who feel strongly about an issue, regardless of whether they are sadly lacking in current knowledge.

Part of the problem is the lack of connection between the policy makers and the "fact makers" or researchers. Often seen as isolated and existing in the ivory tower, researchers are more likely to communicate their work among themselves than with the broader public. Thus, those who influence policy making—advocates and special interest groups—must specifically seek out scientists and sift through their work. Advocates have the opportunity, as well as the responsibility, to interpret research findings once they find them.

The University of Washington Center for Disability Policy and Research (CDPR) has since 1992 generated research findings that can play a significant role in state policy
making for people with developmental disabilities. CDPR seeks to involve members of the disability community to assure that the research is appropriately shaped by the core principles and values established within the community. This paper will describe the results of one such partnership: CDPR’s three evaluations of Washington’s Family Support Opportunity Program.

Research, advocates, and one program

Family support programs have become an integral component of all states’ services and supports to people with developmental disabilities and their families. But most states still maintain waiting lists for family support services, in part because of budget constraints.

In 1996, Washington’s family support program provided funds considerably in excess of the national average but enrolled a much smaller share of families. The Division of Developmental Disabilities (DDD) enrolled about 3,500 families in family support, and spending on the program represented 6.1% of the DDD community budget compared with a national average that year of 3.3% of the community budgets in other states. Washington spent $6,759 a year per family enrolled, compared with a national average of only $1,875. But in 1996, Washington enrolled only 39.4 families for every 100,000 people in the state—less than half the national average of 76.4 families.

This created a budget dilemma for the state: how to extend the benefits of its family support program in an environment where little additional funding could be committed. DDD turned to advocacy groups for their assistance in designing a new family support program. The Family Support Task Force, consisting primarily of parents of children with disabilities living in their families’ homes, guided design and implementation of the
new program. Most of the task force members desired to see five general components in the
new program: respite and in-home supports; access to medical services; information about other services available to families; flexible funds for families to use to purchase needed services and materials; and access to other resources—not funded by DDD—in families’ communities.

With this input from families, DDD proposed to the task force a new program that would combine short-term assistance in the form of cash reimbursements to families, in-home support through Medicaid personal care, and access to information about other services and community resources through the newly developed community guide initiative. Cash reimbursements would be made available to families for most materials and services for up to $900 per year (since raised to $1,300 per year). Family members with disabilities would be placed under the home and community-based waiver to obtain Medicaid coverage and Medicaid personal care.

Finally, each family would be given access to a community guide, a person from its own community with extensive knowledge of both disability issues and generic resources. The community guides would meet with each family that desired their services to determine what assistance the families deemed most important. The community guide would then work with families to locate information that would connect those families to needed supports in their communities. Community guides would receive up to $200 per family, per year. (For a fuller description of the community guide initiative, see Romer, Richardson, Nahom, Aigbe, and Porter, Mental Retardation, in press).
After approval by the Family Support Task Force, DDD offered the new Family Support Opportunity Program (FSO) to families as a pilot program. As part of the pilot process, DDD contracted with CDPR to conduct a review.

After surveying 94 of the initial 277 families to enroll in the new program and interviewing another 40, CDPR concluded that while the program had several areas where it needed to clarify its goals and methods, overall it showed great promise for addressing the issues most critical families. Among areas that seemed well received by families were the short-term assistance funds, the in-home supports of Medicaid personal care, and the services of the community guides. But CDPR also found that families felt the program lacked clarity in its goals and just what services were available. After review by the Family Support Task Force and DDD, the Division fully implemented the program statewide while paying particular attention to providing families with better information about services and clarifying the role of community guides.

Two years later, DDD once again asked CDPR to evaluate the progress of the FSO. The results this time were quite gratifying; families reported a distinct improvement in both the program’s approach and outcomes. They were especially pleased with the community guides, and data collected from 312 families using the guides showed that they felt connected to their communities, that their situations were better understood by FSO, their emotional or physical well-being was improved, and it was easier to care for the family member with disabilities. Furthermore, families indicated high satisfaction with finding
service providers, the clarity of information provided, and their role in defining what supports they wanted most. Based on this feedback, DDD once again made modifications to the FSO program. Notably, DDD emphasized the role of the community guide in assisting families to locate appropriate community options for desired supports by refining community guide training curricula and, in three of the state’s six social and health services regions, contracting with outside agencies to recruit and train community guides.

In a third evaluation of FSO conducted in 2001, CDPR received surveys from 925 families about their experiences with the FSO. The results showed continued improvement in the program. Family ratings of how well the program met their needs were all higher than those obtained in the 1999 review. Due in large part to the continued efforts of three groups—DDD, the Family Support Task Force, and CDPR—the FSO program has been able to address the desired need for support of more than 6,000 families in Washington. Families consistently give the FSO high marks, and more families are enrolled than would have ever been possible given the budget of the old family support program.

The researcher-advocate partnership
The FSO experience shows the benefits of researchers, policy makers and consumers working together to influence public policy. Another such partnership has effectively influenced mental health services. Advocates for the mentally ill have often identified research on mental illness as their highest priority, calling for substantial government investment. Consequently, mental health researchers have considerable incentives to
work closely with the advocacy community, both to assist in interpretation and application of findings and to guide the direction of future research.

There are reasons why other advocates and researchers have yet to achieve such a partnership for disability policy. Disability advocates represent a broad range of organizations, reflecting the variety of factors and conditions contributing to disability. There is no common voice, so it is difficult to coalesce around common issues as the mental health advocacy community has done. In fact, many in the disability community perceive investment in research as diverting resources that are needed to provide services to people with disabilities. In fact, further research and attention to disability issues would benefit all involved.

Four standards should guide this partnership:
1. Research, by definition, reflects social values. The disability community has worked very hard to define the fundamental values driving services and policy. Disability research needs to be predicated on this value base.
2. Advocacy organizations have a responsibility to influence public policy in a way that will guide the research agenda and promote appropriate investment in research.
3. Scientists have the responsibility to communicate their research and its findings to a broad public audience, including those with disabilities and those who advocate for them.
4. Advocates and scientists should work together to ensure that public supports and services are truly available to those who need them, regardless of language, culture, or other potentially limiting factors.

Challenges to assuring equal access, independence, and full community integration for persons with disabilities remain significant and, in a retreating economy, they continue to grow. Meeting these challenges will take hard work on the part of all communities vested in making changes, including research. It is incumbent upon the advocacy communities to reach out and support disability research, whether aimed at changing individual situations or broad public policies. And it is incumbent upon the research
community to listen, involve advocates and consumers in shaping the research agenda, and assure that findings and results are communicated widely and effectively.