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ABSTRACT

This historical paper focuses on improving the dissemination of research results to persons with disabilities and their families. It discusses how to determine the nature and form of the information to be disseminated, as well as the methods for reaching intended audiences. Recommended state-of-the-art methods of dissemination for making research findings accessible to families include: (1) translating research results into practical, useful strategies, products, and ideas; (2) providing research results in articles or monographs that summarize research results in relation to a particular topic, problem, or question; (3) using interactive situations, such as workshops or other training sessions, to provide information to families; (4) using electronic bulletin boards; (5) using public service announcements or longer educational programs, or videotapes that are loaned free of charge to families; and (6) including parents in the development of ideas, the planning of specific projects, and in discussions about the most useful ways to package and disseminate research findings. (Contains 14 references.) (CR)

IMPROVING DISSEMINATION OF RESEARCH RESULTS FOR PERSONS WITH DISABILITIES AND THEIR FAMILIES

Prepared for the
Value-Based Family Research Conference

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This paper focuses on improving the dissemination of research results to persons with disabilities and their families. Implicit in this discussion is a concern about both the nature and form of the information to be disseminated (i.e., how useful and understandable is the information?) as well as the methods for reaching intended audiences (i.e., how best can we assure that family members have access to this useful information?). Johnson, Frazier and Reddich (1983) and Scholl (1983) provide good discussions of the problems of linking research and practice.

These two concerns (the usefulness of research-generated knowledge and the methods of dissemination) will be taken into account as the following questions posed by the conference organizers are addressed: (1) how have research results been disseminated in the past? (2) what factors influence the choice of dissemination strategies? (3) how have these methods not been useful for or accessible by families? (4) what are families' preferences for dissemination given the range of family interests and knowledge? and, (5) What are state-of-the-art methods of dissemination that would be more useful and accessible to families? What are the responsibilities of researchers and families?

How have research results been disseminated in the past?

Responding to this question requires a look first at the general scientific community, and then at Research and Training Centers specifically.

General Issues Looking first at the methods of research dissemination in general, two things are clear; first, most research occurs in universities (Glaser, Abelson and Garrison, 1983; Mulkay, 1972), and secondly, the most frequently used dissemination mechanism for research results is publication in scientific and professional journals (Gordon, 1981). Gordon (1981) studied the dissemination of research funded by the Department of Health and Social Security in the United Kingdom, and concluded that there, too, researchers tended to communicate primarily to fellow specialists-researchers, rather than to practitioner groups or consumers. He suggested that the fixed term nature of research funding compounds the problem by limiting the opportunities for multiple dissemination strategies. In other words, many researchers publish first in scientific journals, and do not find other outlets for the information.

The general inaccessibility and inappropriateness of journals as a dissemination mechanism for persons outside of the scientific community is well known to all of us. Barriers posed by this mechanisms include (1) the lack of mechanisms for family members and others not in academic environments to learn about relevant research, (2) lack of access to library and copying facilities posed by barriers such as distance, costs, and in some cases, skills such as reading level or lack of ability to read English , and (3) the fact that much research is not designed or reported with usefulness in mind. Even much so-called "applied research" does not make direct links between findings and immediate application.

Despite the heavy reliance on journal publications by academics, research results are now being reported in the popular media (television, radio and newspapers) more often than in the past. Although this means that a much wider public is likely to learn about selected research results, this practice carries with it some problems. First, choices about which findings will be featured are often related to the timeliness, or uniqueness of the research issue, rather than to the immediate usefulness of findings. And, there is concern that the results of studies may be over-interpreted or misapplied. In fact, it has been suggested that certain findings that are not fully understood and do not have immediate applicability should not be reported without some instruction about how they should or should not be used.

An example of this dilemma is the recently reported relationship between alcohol intake and breast cancer published in the New England Journal of Medicine, and widely reported in the popular press. The findings are correlational, i.e., the incidence of breast cancer and the alcohol intake appear to increase together, but that's all that's known. Not nearly enough is known to give individual women advice about how to behave.

Other non-academic avenues that increasingly serve as outlets for research findings include advertising and other strategies designed to influence attitudes and behavior, such as political campaigns, and campaigns to sway public opinion, or change policy by a variety of special interest groups ranging from the National Rifle Association to Handgun Control, Inc. Currently, there is no general mechanism for sorting, summarizing and disseminating research results, although there are increasing numbers of clearinghouses and information centers associated with specific problems, or populations (e.g., NICHCY; self-help clearinghouses, consumer protection organizations, and so on).

Research and Training Centers. Research and Training Centers (RTC's) are required by law to be affiliated with universities, and their dissemination strategies tend to reflect those of the general scientific community, i.e., to employ traditional academic approaches to dissemination, such as books, journal articles, and professional conferences. An assessment of the RTC program published last year (Policy Studies Associates & InfoUse, 1988) reported that the two major dissemination vehicles of RTC's were distribution of research papers and presentations at national or regional conferences.

In addition to these traditional methods, however, RTC's employ a wide variety of dissemination strategies and at least some of them state as a goal the translation of research results into practical ideas, products, and practices. This reflects the explicit goal of the Research and Training Center (RTC) program to improve rehabilitative services through research (Policy Studies Associates, Inc. & InfoUse, 1988).

RTC's appear to employ more practitioner- and consumer-oriented dissemination strategies than is the norm in the general research community. For example, of the 50,000 people who participated in Center training activities during 1985, 35 percent were clients and family members (Policy Studies Associates & InfoUse, 1988). Nearly all of the Centers reported having mailing lists (the number of people ranged from 50 to 80,000), and more than half of the Centers published one or more newsletters or journals. Some of the RTC 's include brief summaries of research results in their newsletters, as well as making complete research reports available.

Other dissemination methods include at least one RTC newsletter (ON-LINE, 1985) that is available in audio form over the telephone. The RTC at the University of Wisconsin-Stout also plans to publish newsletters focused on specific audiences, including a Consumer Digest for clients and family members. Other methods include films and video-tapes (e.g., the Native American RTC in Tucson, Arizona), and various training opportunities. These include short-term training (RTC Connection, 1988), internships, regular workshops and institutes.

The assessment of RTC's concludes that "relatively few Centers achieved a balance of outstanding research and effective translation of new knowledge into improvements in the rehabilitation system" (Policy Studies Associates & InfoUse, p. ix). A number of RTC's were characterized as primarily research centers, with limited emphasis on dissemination, while others were seen as primarily emphasizing training. This suggests that there may be some built-in forces that make the balance between research and consumer-oriented dissemination difficult to achieve.

What factors influence the choice of dissemination strategies?

The location of RTC's within universities has important implications for the nature of the research that they do, whether they spend the effort to translate research findings into usable products, ideas and practices, as well as for the dissemination methods chosen.

Understanding the influence of the university setting on choices of dissemination methods requires an understanding of its reward system and culture. There is considerable evidence that the most important rewards within the academic community are attached to professional recognition. As Glaser, Abelson and Garrison (1983) state, "...although researchers may be motivated by the concern to solve certain socially defined problems or by desire for extra financial returns..., it is likely that their contributions to knowledge will be rewarded mostly by various forms of desired recognition. Moreover, that recognition will depend on conformity to expectations of 'appropriateness,' operating within the research network" (p. 362). These authors also comment that sanctions in the university may inhibit the development of applied knowledge and the application of theoretical knowledge.

Examination of the promotion and tenure guidelines for almost any U.S. university today will reveal that although four or five criteria for promotion and tenure are identified (e.g., teaching, research, university service, community service, professional development), a heavy emphasis on research and publications often obscures attention to the other criteria (Stahl, Leap & Wei, 1988). Further, although many kinds of "research and publication" are officially recognized, publication in peer-reviewed journals is often considered the only true test of the faculty member's contribution and worth. Other products such as unpublished research reports, monographs, family handbooks or training materials are considered largely irrelevant (Euster & Weinbach, 1986).

This situation poses serious problems for RTC staff who are also faculty on tenure track appointments. The goals of developing and disseminating practical, usable products and ideas on the one hand, and of gaining academic recognition and rewards on the other are competing, at best, and at times are in direct conflict with each other. Energy and resources devoted to developing products and materials other than journal articles detract from the scholar's pursuit of tenure, and these activities are often viewed with suspicion and dismay by colleagues. This is the "suitability and appropriateness" issue identified earlier by Glaser, Abelson and Garrison (1983).

The pattern of research, development and dissemination (RD&D) used in industry is closer to the model of the Research and Training Center program than is the traditional academic research pattern. Glaser, Abelson and Garrison (1983) also suggest that the linear approach (research first, then dissemination) is increasingly being replaced by circular models, in which the need for new knowledge can be identified at any point in the process, and knowledge may be generated at any point in the research and dissemination circuit. This suggests, for example, that training sessions organized primarily for the purpose of disseminating information may in fact generate new insights and ideas that will stimulate further formal research. It also suggests that we might begin with meetings and conferences as ways to gather information about the information needs and preferences of potential consumers such as family members, rather than thinking of meetings and conferences as solely dissemination vehicles.

How have those methods not been useful for or accessible by families?

We have already examined some reasons why publication in scientific and professional journals is generally not accessible to family members, practitioners, and other non-academics. Problems of accessibility include geography, cost, the technical nature of many research reports, and the problem of knowing where and when to look for possibly relevant studies.

Important to this discussion, as well, is the fact that the accepted standards for content of professional journals do not generally extend to suggesting immediate uses for findings. In fact, as Glaser, Abelson and Garrison (1983) point out, attempts to apply scientific findings directly to realistic social settings are viewed by most "pure" scientists as "mere vulgar popularizations" (p. 370). (See also National Science Foundation, 1969).

What are families' preferences for dissemination given the range of family interests and knowledge?

Unfortunately, there has been little study of family preferences; I hope that this conference may contribute to changing that situation. Because we have no systematic information, and also because "families" encompass a wide range of needs, preferences, educational levels and other factors, it is impossible to generalize about them. Based on the pattern of orders for materials from our RTC and both formal and informal feedback about the usefulness of our products, I will make a few suggestions, and hope that Polly Arango will know more.

First, family members most frequently order materials such as our parent handbook, training materials, and articles and monographs focusing on topics of particular interest to them, such as respite care or transition. These products represent a wide range of sources of information. For example, the parent handbook, drafted for us by a parent, is not the result of a specific study, but is certainly a "research" product in the broadest sense; it is based on scientific information and is well referenced. Our monograph on respite care is based partially on a study of respite programs throughout the country. Parents are also interested in more traditional research results, however, when the content is of interest to them, such as information found in our parent survey.

In terms of dissemination methods, we have had very good feedback from family members who have attended Families as Allies conferences around the country. These conferences are specifically designed to include at least 50 percent family members, and their programs are geared to family and practitioner interests.

Products and materials apparently of less interest to family members are annotated bibliographies, published journal articles, and other research reports.

Overall, it is my impression that the majority of family members with whom we have contact want practical, useful information that is in understandable language, and of digestible length. They find both written materials and interactive dissemination methods, such as workshops and meetings, very useful. It should be noted, however, that many parents do not have the time, the resources (e.g., conference fees, travel expenses, childcare), or the inclination to attend training sessions or conferences. They may prefer other modes, such as books and articles. For those who have the resources, films and video-tapes are also popular.

What are state-of-the-art methods of dissemination that would be more useful and accessible to families?

As in the other sections, it is important to consider both the form and content of research results here, as well as dissemination methods.

Form and content of research. To reiterate, research results will be most useful to family members (and to practitioners and policy-makers, as well) when they are translated into practical, useful strategies, products and ideas.

This requirement imposes a strain on the researcher, not only because of the nature of the academic reward system, but because of the real and legitimate difficulty of drawing valid conclusions and making action recommendations on the basis of one or a few studies. Particularly if the research is designed more to build a knowledge base (e.g., to explore a model of how families use community resources) than to solve a problem or address a challenge (e.g., develop strategies to promote the involvement of families in the evaluation of services), it may be difficult to produce immediately applicable recommendations beyond a discussion of the possible implications of the findings, in the light of previous studies. To help bridge the gap between research and application, Krathwohl (1974) suggests that researchers may need to modify their view of themselves as producers of knowledge toward that of "producers of findings to be confirmed in practice" (p. 83).

Methods of dissemination that may increase the accessibility of research findings to family members include articles or monographs that summarize research results in relation to a particular topic, problem or question (e.g., respite care or the management of aggressive behavior), or interactive situations, such as workshops or other training sessions, when they are appropriate. For some families, information disseminated on electronic bulletin boards may be useful, either directly, or through a parent group that is a bulletin board subscriber.

Dissemination Methods. Methods that are free or low-cost that allow family members to use materials in their own homes may overcome many of the accessibility problems mentioned earlier. These may include public service announcements, or longer educational programs on educational or cable television networks, videotapes that are loaned free of charge to families, and informational messages available on audio-tape by telephone (such as is provided by Mental Health Associations in some parts of the country). In addition, we must address the needs of families for whom English is not the primary language, and those who need other assistance, such as whose with impaired vision or hearing.

Responsibilities of researchers and family members. Central to improving the usefulness of research and the accessibility of research-related information for families is the concept of partnership. Research results will be of interest and relevance to family members when they are included in the development of ideas, the planning of specific projects, and in discussions about the most useful ways to package and disseminate research findings.

Achieving this partnership requires a willingness on the part of researchers to include family members in all phases of the research process, and a willingness on the part of family members to participate. Other mechanisms for learning about family needs and preferences, such as need assessment surveys, and evaluations of materials and training sessions should be developed by researchers. The success of such strategies, of course, is dependent on the participation of family members by completing and returning the needs assessment questionnaires, evaluation forms, and other requests for information.

Family members can also be supportive to researchers by taking into account the nature of the academic environment, i.e., having empathy for the problems faced by the RTC researcher, and <u>not</u> demanding that every research endeavor produce immediately usable results. Such a demand is inappropriate, for, in addition to the constraints of the academic environment, the nature of knowledge-building often requires an accumulation of information about a specific question or problem before practical improvements in services, or useful products can be developed. This is probably the most difficult request of all, since it calls on the generosity and goodwill of family members who will participate in and support research that may bring no immediate (or even eventual) assistance or relief for their family. For researchers, it requires patience, and the ability to live with the helplessness involved in knowing and caring about families we cannot directly help.

Changing the nature and dissemination of disability research so that it is more relevant and useful to families will not be easy. Together, however, researchers and family members can work together to increase the likelihood that RTC research endeavors will contribute to the improvement of services for persons with disabilities and their families.

REFERENCES

Euster, G.L. and Weinbach, R.W. (1986). Deans' quality assessment of faculty publications for tenure/promotion decisions. Journal of Social Work Education, 3, 79-84.

Glaser, E.M., Abelson, H.H., & Garrison, K.N. (1983). Putting Knowledge to Use. San Francisco: Jossey-Bass.

Gordon, M.D. (1981). The dissemination strategies of researchers working in the field of health and personal social services. Social Science Information Studies, 1(5), 307-316.

Johnson, K.W., Frazier, W.D. and Riddick, M.F. (1983). A change strategy for linking the worlds of academia and practice. The Journal of Applied Behavioral Science, 19(4), 439-460.

King, K.P. (1980). The reward system in sociology departments: What we always knew-or did we? Sociological Focus, 13(2), 155-171.

Krathwohl, D.R. (1974). An analysis of the perceived ineffectiveness of educational research and some recommendations. Educational Psychologist, 2, 73-86.

Mulkay, M.J. (1972). Conformity and innovation in science. The Sociological Review Monograph, 18, 5-23.

National Science Foundation (1969). Knowledge into Action: Improving the Nation's Use of the Social Sciences. Report of the Special Commission on the Social Sciences of the National Science Board, Report NSB 69-3. Washington, D.C.: U.S. Government Printing Office.

Native American Research and Training Center. (n.d.) Videotapes Currently Available from the Native American Research and Training Center, Tucson, Arizona.

Policy Studies Associates, Inc. & InfoUse. (1988). Assessment of the Rehabilitation Research and Training Centers Program. Final report prepared for the Rehabilitation Services Administration, U.S. Department of Education. Washington, D.C.

Scholl, G.T. (1981). Bridges from research to practice in education of visually handicapped people. Journal of Visual Impairment & Blindness, ?(?), 340-344.

Stahl, M.J., Leap, T.L. and Wei, Z.Z. (1988). Publication in leading management journals as a measure of institutional research productivity. Academy of Management Journal, 31(3), 707-720.

Stout Vocational Rehabilitation Institute (1988). The RTC Connection, 9(1). University of Wisconsin-Stout, Menomonie, Wisconsin.

West Virginia Research & Training Center (1985). On Line, 2(1). Dunbar, West Virginia.

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