

## DOCUMENT RESUME

ED 344 358

EC 301 084

AUTHOR Turnbull, H. Rutherford, III; Turnbull, Ann P.  
TITLE Participatory Action Research and Public Policy.  
INSTITUTION Kansas Univ., Lawrence. Beach Center on Families and Disability.  
PUB DATE 91  
NOTE 25p.  
PUB TYPE Viewpoints (Opinion/Position Papers, Essays, etc.) (120)

EDRS PRICE MF01/PC01 Plus Postage.  
DESCRIPTORS Action Research; Change Strategies; Cooperation; \*Disabilities; Government Role; \*Models; \*Participatory Research; Qualitative Research; \*Rehabilitation; Research Design; \*Research Methodology; Standards  
IDENTIFIERS National Institute on Disability Rehab Research

## ABSTRACT

This paper describes collegial model approaches to the interactions between rehabilitation researchers and individuals with disabilities or their family members. The approaches, called participatory research and participatory action research, grew out of a 1989 conference sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR) and out of a 1991 conference presentation by the director of NIDRR. A rationale for use of a model of participatory research is presented, and the model is described as involving its subjects in the research process from initial design to final conclusions. Five principles that should guide research on people with disabilities and their families are presented, including: research is a means, not an end; research should be a collaborative endeavor based on mutual respect, trust, potential benefits, and acceptance of each party's responsibilities; research should be sensitive to cultural, socioeconomic, ethnic, lifestyle, and life span pluralisms; research should allow for a combination of paradigms and methodologies; and funding for family research should be expanded. Forces creating pressure to support a shift in research paradigms are outlined, and the role of the NIDRR in support of the model is discussed. (Seven references) (JDD)

\*\*\*\*\*  
\* Reproductions supplied by EDRS are the best that can be made \*  
\* from the original document. \*  
\*\*\*\*\*

U.S. DEPARTMENT OF EDUCATION  
Office of Educational Research and Improvement  
EDUCATIONAL RESOURCES INFORMATION  
CENTER (ERIC)

- ☐ This document has been reproduced as received from the person or organization originating it
- ☐ Minor changes have been made to improve reproduction quality

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy

"PERMISSION TO REPRODUCE THIS  
MATERIAL HAS BEEN GRANTED BY

Harriet  
Chapman

TO THE EDUCATIONAL RESOURCES  
INFORMATION CENTER (ERIC)."

# **Participatory Action Research and Public Policy**

**PO-8**

**H. Rutherford Turnbull, III, and  
Ann P. Turnbull**

**1991**

© Beach Center on Families and Disability  
The University of Kansas, 1991.

# **PARTICIPATORY ACTION RESEARCH AND PUBLIC POLICY**

by

**H. Rutherford Turnbull, III**

and

**Ann P. Turnbull**

In recent years, American industry has come to appreciate the so-called "Japanese model" for management and research. Briefly stated, that model proposes that management, including research and development units, should consult the line-workers in almost all matters relating to the industry's operations. In the disability field, that model has begun to be applied to the interactions between rehabilitation researchers and various research consumers.

This article describes two discrete proposals that researchers adopt an essentially "Japanese" or collegial model in working with research consumers, whether they be people with disabilities or family members. The two proposals are called participatory research and participatory action research. Both have emerged from the work and thinking of rehabilitation researchers. One grew out of a 1989 conference, sponsored by National Institute on Disability and Rehabilitation Research (NIDRR), that consisted of researchers and family consumers. The other recently was made by Dr. William Graves, NIDRR director. This article describes the two proposals and advocates for the model of participatory research.

## **Reasons for Proposing the New Model**

There are at least two reasons why a model of participatory research is becoming attractive to rehabilitation researchers. The following section briefly describes those reasons.

### ***The Credibility Gap***

For several years, it has been apparent that rehabilitation or other disability research has experienced what might be politely and accurately called a credibility gap. Another

name for it might be the relevance gap. Dr. Graves noted this in his keynote address to the 1991 annual meeting of the National Association of Rehabilitation Research and Training Centers.

Disability and rehabilitation research. . . . is viewed not only by practicing rehabilitation counselors as impractical, but often by people with disabilities as irrelevant. The credibility problem points out that disability and rehabilitation research not only has the traditional and age old problem of closing the gap between the researcher and the end user of the research. It also has the problem that too few view it as worth taking the time to close the gap between research and practice.  
(pp. 17-18)

Others have referred to the gap as one of relevance and have advocated that research should be valued only as it serves the interests of research consumers. That is a position that the senior author of this paper took (Turnbull, 1986). It also is the same position adopted by a subsequently formed ad hoc committee that worked on the relevance issue with the National Institute of Child Health and Human Development on behalf of the American Association on Mental Retardation, the National Down Syndrome Congress, Division 33 of the American Psychological Association, the Association for Retarded Citizens—United States, and The Association for Persons with Severe Handicaps.

With respect to research and its relevance to people with disabilities and their families, it is notable that, over the past decade, organizations such as the Association for Retarded Citizens—United States and The Association for Persons with Severe Handicaps have not given high priority to increasing research dollars, despite the fact that professionals and organizations representing them have consistently testified in favor of increasing those funds. It is more than arguable that, for the organizations representing the end consumers, research has been a relatively low priority because research has been of relatively low utility to them.

### *The Funding Gap*

It should not be surprising to those who believe that funding reflects policy to learn that rehabilitation research funding has not been enjoying a boom. The most comprehensive data on research funding are those assembled by Braddock (1987a, 1987b). Braddock has analyzed research support in the area of mental retardation and other developmental disabilities for the period beginning 1955 and ending 1977, including all federal funding agencies, and also including all research on the three major areas of emphasis: (a) education, (b) vocational rehabilitation, and (c) biomedical, behavioral, and health services research.

His conclusions are that there have been consistent declines in federal support for mental retardation and developmental disabilities since approximately 1971, following a consistent rise in that research funding during the period starting in FY 1954 and ending in FY 1971. Similar declines in federal funding for personnel training also have occurred. During these same periods of time, however, federal support for direct services and income maintenance programs has increased. The argument can be made that research funding has declined because consumers such as those with disabilities, their families, and service providers regard it as less useful than direct services. Without reaching that conclusion directly, Braddock (1987a) notes:

The success of this nation's efforts to prevent mental retardation and other developmental disabilities and to provide humane, professional care in integrated community settings is dependent on the adoption of long-term federal financial incentives, on the systematic expansion and application of the field's knowledge-base, and on an adequate and continuing supply of caring and competent personnel. Thus, it is essential for MR/DD research and training activities to be re-established as funding priorities of the U.S. government. Achieving this objective will require MR/DD researchers to join with those in the general social and biomedical sciences to press for increased support for research and training in general. Equally

important, achieving this objective will also require the MR/DD research community to more clearly and convincingly articulate why scientific research and training is an efficacious investment of scarce public resources. (p. 185)

Having considered two reasons why rehabilitation-related research funding and the sources of support for rehabilitation researchers have declined, it is now appropriate to address the participatory research or participatory action research model and its relevance to rehabilitation research consumers.

### **Participatory Action Research: A Possible Solution**

As Dr. Graves noted (1991), participatory action research (PAR) may be a powerful tool for advancing both science and practice. Whyte (1991) said that PAR involves practitioners in the research process from the initial design of the project through data gathering and analysis to final conclusions and actions arising from the research. He indicated that PAR evolved out of three streams of intellectual development and action: (1) social research methodology; (2) participation in decisionmaking by low-ranking people in organizations and communities; and (3) organizational behavior in sociotechnical systems.

The first two of these are relevant to rehabilitation researchers. The "professional expert" model is the most common type of applied social research. In this form of research, the professional has complete control of the research progress except to the extent that the research subject limits some of the research options. Whyte explained that this type of research is perfectly appropriate where the objectives of both the researcher and the decisionmakers are simply to get the facts and examine action implications.

Those researchers and managers who seek to help organizations carry through major processes of sociotechnical change, however, have come to recognize limitations of the professional expert model. Whyte suggested a need to develop a process of change, resulting in organizational learning, over a considerable period of time. To be useful in

stimulating and guiding this process, the researcher cannot simply stand aside and merely report research findings to the decisionmakers.

An alternative research model is participatory action research. Rather than treating the practitioners of the technologies as passive informants, PAR involves them as active participants in research (Whyte, 1991). Researchers inviting their subjects to participate with them in the research process may be appropriate for some organizations, but is it appropriate for rehabilitation researchers? That was the question that both the NIDRR conference in 1989 and Dr. Graves in 1991 addressed, with remarkable insights and notable agreement in perspectives. The conference concluded that participatory research is indeed warranted, and Dr. Graves began his address by commenting on the NARRTC conference theme, "Effective Consumer Involvement and Scientific Excellence:"

this theme demonstrates to scientists in this and other fields that the inclusion of people with disabilities in the research endeavor is not antithetical to the scientific method and indeed this inclusion may result in more effective services, programs, and products. (p. 1)

### **Participatory Action Rehabilitation Research**

The 1989 NIDRR-sponsored conference on rehabilitation research that affects families focused initially on a seemingly simple question: What principles should guide research on people with disabilities and their families? That was the question that 16 people with family members with disabilities and 16 researchers sought to answer. (The conference was coordinated by the Beach Center on Families and Disability, a rehabilitation research and training center on families based at the University of Kansas. A report of that conference, entitled "Report of Consensus Conference on Principles of Family Research," was prepared by the authors of this article and other senior staff of the Beach Center and is available from the Beach Center. This article excerpts from that report.)



Interestingly, the issue of guiding principles is one that NIDRR itself has addressed as part of its annual goal-setting and goal-achievement process. In the spring of 1991, Dr. Graves noted two relevant goals: to “increase the quality and quantity of advice and input from individuals with disabilities” (p. 2), and “to increase the contributions, especially in technology, to improvements in the quality of life for persons with disabilities” (p. 4).

As conference participants wrestled with the question of guiding principles, they confronted other questions (Turnbull & Turnbull, 1989):

- What processes should federal agencies, researchers, and families follow in formulating research questions and identifying research priorities?
- What values and practices should guide procedures to obtain informed consent and to ensure that no harm comes to families participating in research?
- What research sampling strategies will increase participation by all family members and by underrepresented groups of families?
- How can research methodologies become more respectful of families?
- How can research results be disseminated to families more effectively? (p. 1)

After two full days, participants agreed on these five principles (Turnbull & Turnbull, 1989):

1. Research is a means, not an end. Its goals are to develop information and test strategies and interventions that themselves are designed to accomplish certain goals. Those goals are to:
  - expand choices;
  - build on strengths;
  - promote independence and productivity;
  - promote integration in school, work, recreation, residence, and other community environments;
  - expand relationships and friendships within family and community;
  - recognize and expand positive contributions;

- identify challenges and enhance the capacity of all family members to meet them;
  - change systems to promote the foregoing purpose;
  - expand visions and possibilities;
  - improve the basic and theoretical understanding of families; and
  - prevent and ameliorate the effects of disability.
2. Research should be a collaborative endeavor based on mutual respect, trust, potential benefits, and acceptance of each party's responsibilities.
  3. Research should be sensitive to cultural, socio-economic, ethnic, lifestyle, and life span pluralisms.
  4. To achieve the foregoing purposes, research should allow for a combination of paradigms and methodologies.
  5. Funding for family research should be expanded to adequately achieve the stated principles. (pp. 1-2)

It is remarkable that Dr. Graves (1991), elaborating on the NIDRR goal to improve the quality of life of individuals with disabilities, commented:

The research program at NIDRR must increasingly be one that facilitates empowerment or self-reliance of people with disabilities and their families. The research and training programs of the RTCs must be undergirded by empowerment principles. This goal is essentially one of determining the impact of the projects NIDRR funds on the quality of life of people with disabilities. . . .

The intent of the NIDRR research policy is to foster research and training activities that empower and those that complement the rehabilitation philosophy of self-reliance, independence, and dignity of the individual with a disability. (p. 5)

From the very beginning, the 1989 conference sought to forge a partnership among families and researchers. In practical terms that meant:

- There should be equal numbers of families and researchers.

- The issue had to reflect family and researcher concerns.
- There had to be significant participation of families from groups that have often not been involved in research, such as minorities and single parents.

In order to accomplish these goals, Beach Center staff asked a large number of family researchers to identify families who had participated in research projects and who would be willing to talk about research-related concerns. Family participants were selected on the basis of their leadership in state and national advocacy organizations and on the nomination of advocacy organizations.

Researchers participating in the conference were selected on the basis of three criteria: 1) involvement in a family research project; 2) project funding by NIDRR; and 3) concern for developing genuine partnerships with families reflected in their current and previous research. As a result, an equal number of family members and researchers participated in the conference. Nine of the 16 family members (or 56%) were from traditionally underrepresented groups (single parents, fathers, Blacks, Native Americans, and Hispanics). Four of the 16 researchers came from families with members with disabilities.

To focus the conference discussions, Beach Center staff developed five broad questions. These corresponded to the five stages of the research process. One family member and one researcher prepared brief discussion papers for distribution to all participants in advance. The conference began with two plenary sessions at which the authors of the papers summarized their points of view. Participants then formed five small discussion groups, one group for each question. Those groups met for six hours and prepared group reports. Then representatives from each group synthesized the discussions and developed a set of five principles. A final plenary session gave all participants an opportunity to discuss, modify, and eventually adopt these principles.

As these excerpts make clear, the participants—first as individuals presenting papers, next as members, and finally as participants in a plenary-session discussion—

developed a consensus about principles of family research. They also agreed that the principles should be followed by all federal research-funding agencies and all researchers whose activities affect families, people with disabilities, or both.

### *Purposes of Conference*

NIDRR officials (Karp, 1989) stated that the conference should:

- recommend procedures and standards to help federal agencies sponsor research that will help families' needs and enhance their strengths.
- recommend procedures and standards to help federal agencies develop data bases that can be used to show policymakers how to support families.
- recommend how researchers can design rigorous yet practical research that will:
  - \* maintain families' sense of dignity and privacy.
  - \* consume very little of the families' time.
  - \* help families feel that their member with a disability, like other family members, has a positive impact as well as a negative impact on their lives.
  - \* help provide strategies and models for families to become part of the fabric of their communities, not just people in communities.

Just two years later, Dr. Graves (1991) articulated similar concerns about the methods of research and their effects on and utility for research consumers.

In traditional approaches to disability and rehabilitation research, the role of the person with a disability is that of a subject, an object to be investigated. The problem investigated is usually defined as a physical, sensory, cognitive, or mental impairment, employability, functional limitations, or lack of motivation and cooperation of the person with the disability. The locus of the research problem is in the individual with the disability. The research strategy is usually determined by the researcher. The strategy is often an intervention designed by the rehabilitation professional or researcher addressing the problem identified by the researcher. The intervention usually focuses on evaluation, training, or home and job site

modification. The researcher is in control of the research design from the formulation of the research question to the outcomes promoted to the dissemination of the knowledge produced and the products developed. The terms "objective," "nomothetic," and "quantitative" describe the traditional approach to disability and rehabilitation research. It should not be surprising that these terms are used to describe the majority of disability branches of science that use models of scientific investigation based on early 20th Century philosophies of science as logical positivism. Most contemporary disability and rehabilitation research has its roots in methodologies derived from this approach to understanding physical and subjective phenomena. Therefore, it should not be surprising that disability and rehabilitation research methodologies may be characterized as objective, group based or nomothetic, and quantitative. (pp. 20-21)

Dr. Graves (1991) added that philosophy of science characterized by objectionism, positivism, and reduction is growing less attractive in disability and rehabilitation research because of the importance of phenomena that do not fit within the limits of the model. "Science is not achieved by distancing oneself from the subject, but rather from the recognition that the greatest conceptual and methodological challenges come from engagement with the world" (p. 23).

There are several forces creating pressure to support a shift in research paradigms, according to Dr. Graves (1991):

- popular and funding source appraisals of the relevance of issues studied to priority concerns;
- the potential for practical and immediate utility of research findings;
- consumer appraisals of methodological appropriateness;
- consumer appraisals of the accuracy of interpreted findings; and
- accumulating knowledge and technology which at some point tip sciences, disciplines, and entire cultures into new paradigms. (p. 24)

## *Participatory Research*

There is now no doubt that NIDRR will be encouraging the adoption of the PAR approach to disability and rehabilitation research. NIDRR will include statements in the preambles to absolute and invitational priorities that stress the inclusion of the PAR approach in disability and rehabilitation research.

Just two years earlier, the conference stressed the need for this new paradigm (Turnbull & Turnbull, 1989):

- All of those people affected by research should participate together across a wide range of research activities.
- These people include those with disabilities, their families, researchers, and organizations that represent these people.
- Participatory research ultimately is tied to participatory democracy—research that involves the participation of these people parallels a fundamental precept of democratic government, namely that government exists by, of, and for the people.
- Accordingly, research should be conducted in the public interest—that is, for articulated purposes consistent with agreed upon principles.
- In this respect, research is a fundamentally democratic undertaking and therefore should be conducted, in all of its stages, in ways that especially reflect the participation of families and people with disabilities. (p. 5)

The conference noted that participatory research reflects a democratic value—that those who are affected should be involved in the full range of research activities.

Accordingly, five principles for participatory research were developed by researchers and consumers to reflect the theme of participation (Turnbull & Turnbull, 1989):

1. The first principle reflects participation in the purposes and mission of research.
2. The second principle reflects participation in the roles that people carry out.
3. The third principle reflects participation by families with diverse characteristics.

4. The fourth principle reflects participation by researchers with diverse skills.
5. The fifth principle reflects participation by funding agencies. (p. 5)

Table 1 illustrates the relationship between each principle and the theme of participatory research.

The conference report stated that, at a very fundamental level and as the initial step of the research process, participation begins when all of the affected people can have roles in stating the research's purpose. This is because research is a means, not an end.

### **Principle 1: RESEARCH IS A MEANS, NOT AN END**

*Research is a means, not an end.* Its goals are to develop information and test strategies and interventions that themselves are designed to accomplish certain goals.

Those goals are to (Turnbull & Turnbull, 1989):

- expand choices;
- build on strengths;
- promote independence and productivity;
- promote integration in school, work, recreation, residence, and other community environments;
- expand relationships and friendships within family and community;
- recognize and expand positive contributions;
- identify challenges and enhance the capacity of all family members to meet them;
- change systems to promote the foregoing purpose;
- expand visions and possibilities;
- improve the basic and theoretical understanding of families; and
- prevent and ameliorate the effects of disability. (p. 7)



---

**Table 1**

<b>Principle</b>	<b>Participatory Theme</b>
1. Research should be a means, not an end.	1. The First Principle reflects <u>Participation</u> in the purposes and mission of research.
2. Research should be a collaborative endeavor based on mutual respect, trust, benefits, and acceptance of each party's responsibilities.	2. The Second Principle reflects <u>Participation</u> in the roles that people carry out.
3. Research should be sensitive to cultural socio-economic, ethnic, lifestyle, and life span pluralisms.	3. The Third Principle reflects <u>Participation</u> by families with diverse characteristics.
4. To achieve the foregoing purposes, research should allow for a combination of paradigms and methodologies.	4. The Fourth Principle reflects <u>Participation</u> by researchers with diverse skills.
5. Funding for family research should be expanded to adequately achieve the stated principles.	5. The Fifth Principle reflects <u>Participation</u> by funding agencies.

---

**Note:** From Report of Consensus Conference on Principles of Family Research (p. 6) by H. R. Turnbull and Ann P. Turnbull, 1989, Lawrence: The University of Kansas Beach Center on Families and Disability. Copyright 1989 by Beach Center on Families and Disability. Reprinted by permission.



[Conference] participants acknowledged that values do not always precede research, though sometimes they should. There are instances in which research shapes the values. Thus, there is a dynamic interaction between goals, values, and research. In a word, there is participation between the research community and the community of family members, people with disabilities, and service providers. But there should be more participation in shaping research to reflect certain goals. As researchers, family members, people with disabilities, and service providers participate in shaping research to reflect certain goals, they necessarily will share their perspectives about each others' roles, including their expectations for participation in all phases of the research endeavor. It is hoped that the expectations will be that all of them will participate actively throughout the entire spectrum of the research endeavor.

They also noted that these goals shape the research questions, not the research results. For example, research results that ask about positive contributions may not reveal positive contributions. If that is the case, the research questions then might move in the direction of alternative ways to support families and the impact of that support on increasing or decreasing positive contributions. (pp. 7-8)

These conference observations are in line with the NIDRR position on PAR. Dr. Graves (1991) explains that PAR forces researchers to check the facts with people who have firsthand knowledge before reports are presented.

By involving the individuals who have the most to gain from the research effort, more relevant questions will be asked, more relevant and acceptable intervention strategies will be developed, more accurate location of the foci of the research will occur, better dissemination strategies will occur, and more interest and commitment in using the product of the research endeavor will occur. (p. 28)

## **Principle 2: RESEARCH IS A COLLABORATIVE ENDEAVOR**

*Research should be a collaborative endeavor based on mutual respect, trust, benefits, and acceptance of each party's responsibilities.*

The second principle calls on researchers, family members, and people with disabilities to develop new roles, to enter into a different kind of partnership. Like the First Principle, it too reflects the concept of participatory research. Its moving words are “collaborative,” “mutual respect, trust, and benefits,” and “acceptance of each party's responsibilities.” It evokes an image of different parties—researchers, family members, and people with disabilities—being involved in the wide range of research activities. In turn, it demands that each of these groups of people confront each others' purposes, needs, methods, and results, and that they do so by discussing and reasoning together. This principle requires many bridges to be built all throughout America to help the researchers, family members, and people with disabilities cross into each others' worlds, and many conference tables to be furnished so all of these people can work together (Turnbull & Turnbull, 1989, p. 10).

## **Principle 3: RESEARCH SHOULD BE CULTURALLY SENSITIVE**

*Research should be sensitive to cultural, socio-economic, ethnic, life-style, and life-span pluralisms.*

## **Principle 4: RESEARCH SHOULD CONSIST OF MANY PARADIGMS AND METHODOLOGIES**

*To achieve the foregoing purposes, research should allow for a combination of paradigms and methodologies.*

It became clear that participants were making these points (Turnbull & Turnbull, 1989):

- People with disabilities and their families influence and are influenced by many factors, especially the nature of their communities and the legacy of past practices, policies, and programs. This justifies research by many disciplines, particularly those that can learn about and thus help influence practices, policies, and programs. Research by scientists in different disciplines will help because it will ensure that different philosophies, perspectives, and backgrounds will be reflected in the research process.
- People with disabilities, their families, and the general public will benefit from research on systems—economic, legal, political, and other.
- Change in the lives of people with disabilities and their families, their communities, and the practices, policies, and programs that affect them will occur to a greater degree when many research methodologies are supported.
- Thus, to accomplish the goals specified in the First Principle, there needs to be research in behavioral, biological, and bio-behavioral sciences, as well as in education, psychology, economics, policy analysis, law, ethics, history, anthropology, and sociology, to name the most obvious disciplines.
- Research that is limited by a single paradigm or discipline will not be as useful as a program of research that combines different paradigms and methodologies. This does not mean that each research project should reflect multiple approaches to disability and family life or multiple methodologies. But it does mean that research should, in the aggregate, consist of different paradigms and methodologies. (pp. 14-15)

Dr. Graves (1991) expressed similar views in his description of PAR:

PAR is an approach that can be applied to research methodologies characterized as quantitative, qualitative, survey research, evaluation studies, and single-subject design. The researcher who uses the PAR model not only works with members of the organization or community in identifying the research question or diagnosing

the problem, the researcher also draws upon the research literature, as well as his or her own past experience as a researcher or a rehabilitation service provider. PAR helps researchers to be assured that the respondent is answering the question the researcher asked.

PAR has considerable merit for consideration by researchers, policymakers, rehabilitation professionals, and people with disabilities. Few problems in this field arise in such form that they can be solved by one discipline. No researcher can master all of the disciplines relevant for the problems that rehabilitation counselors encounter. In PAR, the researcher acts less as a disciplinary expert and more as a coach in terms of team building and in seeing to it that as much of the expertise available to the problem solution is capable of being used. PAR enables the researcher and the person with the disability to examine major changes that both helped create. (pp. 25-26)

#### **Principle 5: MONEY SHOULD UNDERLIE THE PRINCIPLES**

The participants recognized that new money must be put behind the first four principles in order to put them into effect and reached consensus on enforcing the first four principles by the fifth principle: *Funding for family research should be expanded to adequately achieve the stated purposes.* (Turnbull & Turnbull, 1989)

The fifth principle:

- recognizes that public and private funding for research must be increased.
- acknowledges that funding for research has declined as funding of services has increased.
- calls for additional funding and particularly for research that incorporates the first four principles.

- recognizes that all of the people affected by research must be co-participants in seeking more funding, but they will not be collaborators in that effort until they are satisfied that research conforms to the first four principles. (pp. 15-16)

The matter of funding was put directly and forcefully to the participants by a team that asked researchers to pay family members.

The following recommendations were also made (Turnbull & Turnbull, 1989):

- fund longer term projects to allow for the use of more family-friendly methods, and so that families are not left in the lurch in terms of continued availability of services.
- increase funding for collaborative research efforts between families and researchers, and between large research institutes and small service provider agencies.
- increase funding for interdisciplinary research.
- communicate with funding agencies about research priorities.
- increase funding for alternative research methodologies.
- increase funding for training of family researchers.
- provide adequate funding for dissemination, not just data collection and analysis; when researchers have the funds for dissemination to a wide range of consumers, they have an obligation to fully analyze the data and appropriately disseminate the results in a timely manner. (pp. 16-17)

Dr. Graves (1991) addressed the issue of funding and dissemination:

It makes little sense for taxpayers to support research which is intended to benefit people with disabilities and their families and the information and knowledge produced not get to the intended user. The NIDRR has a congressional mandate to disseminate knowledge and informational materials we collect and produce.

Through the information dissemination process, the NIDRR can empower people with disabilities by making the knowledge and information produced in the NIDRR

programs accessible so that families and individuals with disabilities can make informed choices.” (p. 11)

These comments underscore NIDRR’s efforts to increase the information dissemination activities, especially those related to assistive technology. Dr. Graves’ (1991) commitment in this matter is clear:

NIDRR will work to let people know how information produced by federally funded researchers benefits them as people with disabilities, as family members, as disability and rehabilitation researchers and engineers, and as providers of rehabilitation services to people with disabilities. (p. 12)

More than that, they also reflect the fundamental premise of participatory research, which is that collecting and disseminating research information are means to the end of empowering people with disabilities and their families. (Graves, 1991, p. 11)

### Conclusion

There is a propitious confluence of views concerning rehabilitation research, at least on the basis of the 1989 conference and 1991 commitment undertaken by NIDRR as articulated by its director, Dr. Graves. The conference seemed to be rather advanced, calling for researchers to abandon a fairly common mode of operations and to take up a singularly different one—participatory research. But two years later, to the month, Dr. Graves (1991) was so bold as to say:

Science is not achieved by distancing oneself from the subject, but rather from the recognition that the greatest conceptual and methodological challenges come from engagement with the world. (p. 23)

For NIDRR, as for the 1989 conference participants, the research paradigm that will “lend greater credibility to disability and rehabilitation research” is participatory action research (Graves, 1991, p. 24). Similarly, the 1989 conference and Dr. Graves concur that participatory action research can be applied to various research methodologies—

quantitative, qualitative, survey research, evaluation studies, and single-subject design (Turnbull & Turnbull, 1989, pp. 13-15; Graves, 1991, p. 25). Just as no single discipline can solve all of the problems that have arisen in the field of rehabilitation, so no single expert, whatever the person's discipline, can examine and research the "major changes" in the rehabilitation field "that both helped create" (Graves, 1991, p. 26). For NIDRR, two advantages of participatory action research are in "reducing the credibility problem" and ensuring that

more relevant questions will be asked, more relevant and acceptable intervention strategies will be developed, more accurate location of the foci of the research will occur, better dissemination strategies will occur, and more interest and commitment in using the product of the research endeavor will occur. (p. 28)

Accordingly, the task is not to ensure that participatory action research will be used in rehabilitation research, as it already is used; rather it is to address its underuse. To this end, NIDRR is committed to encouraging the adoption of the participatory action research approach (Graves, 1991, p. 28-29).

NIDRR's decision to encourage participatory action research is consistent with the recommendations from the 1989 conference (pp. 1-2, 5-6). As noted in the introduction to this article, the two gaps that seem to underlie the call for participatory research—the credibility gap and the relevance gap—can be shrunk, if not altogether eliminated, when research is participatory (Graves, 1991, pp. 29-30). For those who have argued that research is an end and not a means, NIDRR's position on participatory action research can only be heartening.



## Reference List

- Braddock, D. (1987a). Federal policy toward mental retardation and developmental disabilities. Baltimore: Paul H. Brookes Publishing Co.
- Braddock, D. (1987b, June). Federal support for research on the mental health aspects of mental retardation: A preliminary analysis. Paper presented at the International Research Conference on the Mental Health Aspects of Mental Retardation, Evanston, IL.
- Graves, W. H. (1991, May). Participatory action research: A new paradigm for disability and rehabilitation research. Paper presented at the annual conference of the National Association of Rehabilitation Research and Training Centers, Washington, DC.
- Karp, N. (1989, May). Opening remarks presented at the Consensus Conference on Principles of Family Research, Washington, DC.
- Turnbull, H. R. (1986). Presidential address to American Association on Mental Retardation. Mental Retardation, 24(5), 265-275.
- Turnbull, H. R., & Turnbull, A. P., and senior staff. (1989). Report of consensus conference on principles of family research. (CF-1). Lawrence: University of Kansas Beach Center on Families and Disability.
- Whyte, W. F. (Ed.) (1991). Participatory action research. Newbury Park, CA: Sage Publications.





**Beach Center on  
Families and Disability**

---

The University of Kansas  
% Institute for Life Span Studies  
3111 Haworth Hall  
Lawrence, Kansas 66045

Co-Directors: Ann P. Turnbull  
and H. Rutherford Turnbull, III

(913) 864-7600  
(913) 864-5323 FAX