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ABSTRACT

This document was prepared in response to the 1992 Rehabilitation Act Amendments (P.L. 102-569), which provide a legal basis for greater consumer involvement in rehabilitation services. The focus of this document is to: (1) show how persons with disabilities can better participate in their rehabilitation programs; (2) lay the foundation for shifting attitudes about this process; and (3) outline how professionals in research and practice can improve their effectiveness through collaboration with all concerned. After an introductory chapter, the second chapter defines terms used in the study. The third chapter considers the historical and philosophical background of the issue of consumer participation. Next is a review of current systems of rehabilitation research and practice and the relationship of these to consumer involvement. The strengthening of applications from research through the involvement of consumers and practitioners is the focus of the fifth chapter. The sixth chapter proposes a methodology for maximum inclusion of consumers, practitioners, and researchers into the traditional research and development methodology. The following chapter applies this methodology in a case study of "how to devise an equitable approach to counselor performance evaluation." The final chapter presents the 12 recommendations. Appendices include a list of study group members and an illustration of the recommended model. Individual chapters include references. (DB)

Consumer Involvement in Rehabilitation Research & Practice

Nineteenth Institute on Rehabilitation Issues

Arkansas Research & Training Center in Vocational Rehabilitation
University of Arkansas at Fayetteville Arkansas Rehabilitation Services

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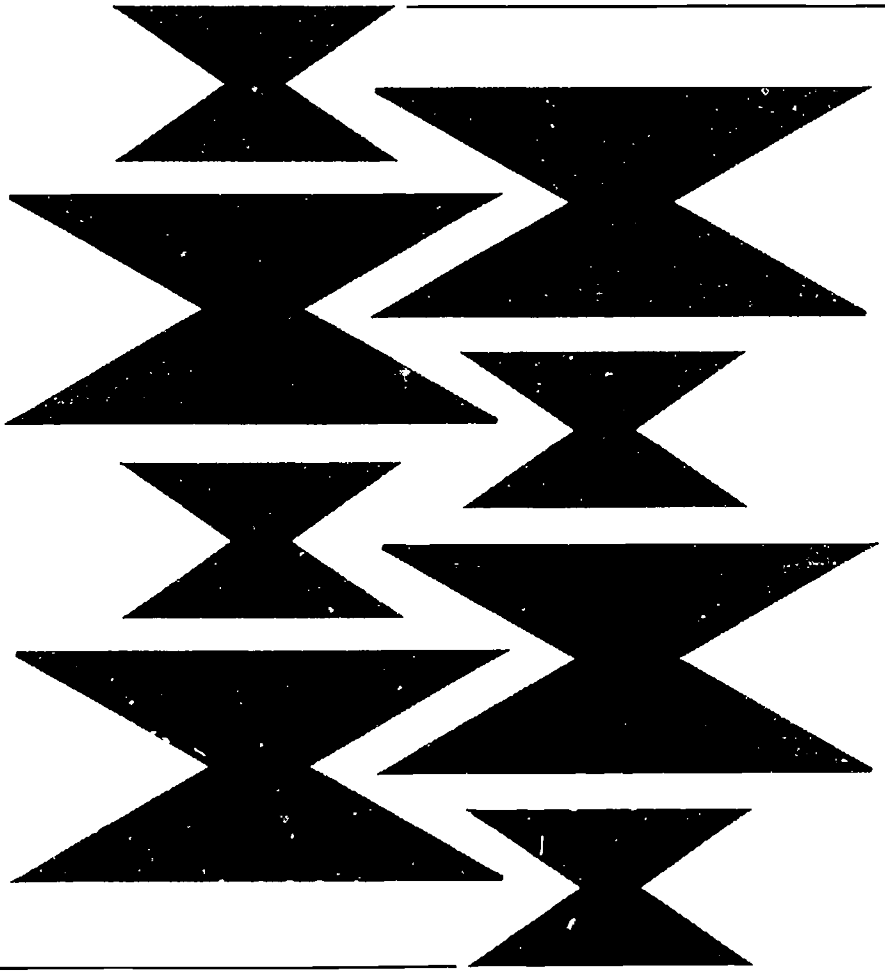
Nineteenth Institute on Rehabilitation Issues

Consumer Involvement in Rehabilitation Research and Practice



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Chairperson's Comments

The National Institute on Rehabilitation Issues (IRI) Planning Committee charged the Prime Study Group with the task of writing a document to serve as a resource for planning, developing, implementing and evaluating programs to help consumers assume their rightful places as partners in rehabilitation research and practice. Although the concept of consumer involvement is not new, it remains an unresolved issue because consumer involvement has not been successfully integrated into the processes of rehabilitation research and practice. This study is unique in that the rehabilitation researcher, the practitioner, and the consumer achieve a "common ground" in the development and realistic application of rehabilitation research results.

Advocates and consumers need to critically review research and promote the practical application and meaningful research results. This collaboration is critical to the task of identifying and coordinating the most efficient and quality oriented methods and services necessary to enable persons with disabilities to return to full and productive lives. This blending of strengths enhances the opportunities for success in meeting the challenges, and will bring innovative opportunities and benefits for the future.

Sincere appreciation is extended to the following members of this outstanding Prime Study Group who willingly gave of their time, creative expertise, and unique perspectives: Douglas Rice, University of Arkansas Research and Training Center in Vocational Rehabilitation (University Sponsor); Frederick E. Menz, University of Wisconsin-Stout; Claire Hymel, Louisiana Rehabilitation Services; Lauren Begam-Brannan, Texas Rehabilitation Commission; Tim Gracey, Iowa Division of Rehabilitation Services; Paul Wright, Michigan Rehabilitation Services; Margaret A. Nosek, ILRU R&T Center on IL, Texas; Joy Kniskern, Georgia Division of Vocational Rehabilitation; Bobby Greer, Memphis State University; and Mary Barnett, ILRU/ADA, Texas.

Gratitude is also extended to those who attended the 19th IRI Annual Meeting. As study group members, they contributed excellent critiques of this document. The Prime Study Group extends sincere thanks to Janice Irwin, Mary Drevdahl, Lou Tabor, and Sandra Parkerson of the Arkansas Research and Training Center in Vocational Rehabilitation for their assistance throughout the duration of the study. Without their help the document could not have been completed and disseminated to the field. Serving as chairperson of these two groups and participating in the IRI process has not only been an honor and a privilege, but a learning experience as well.

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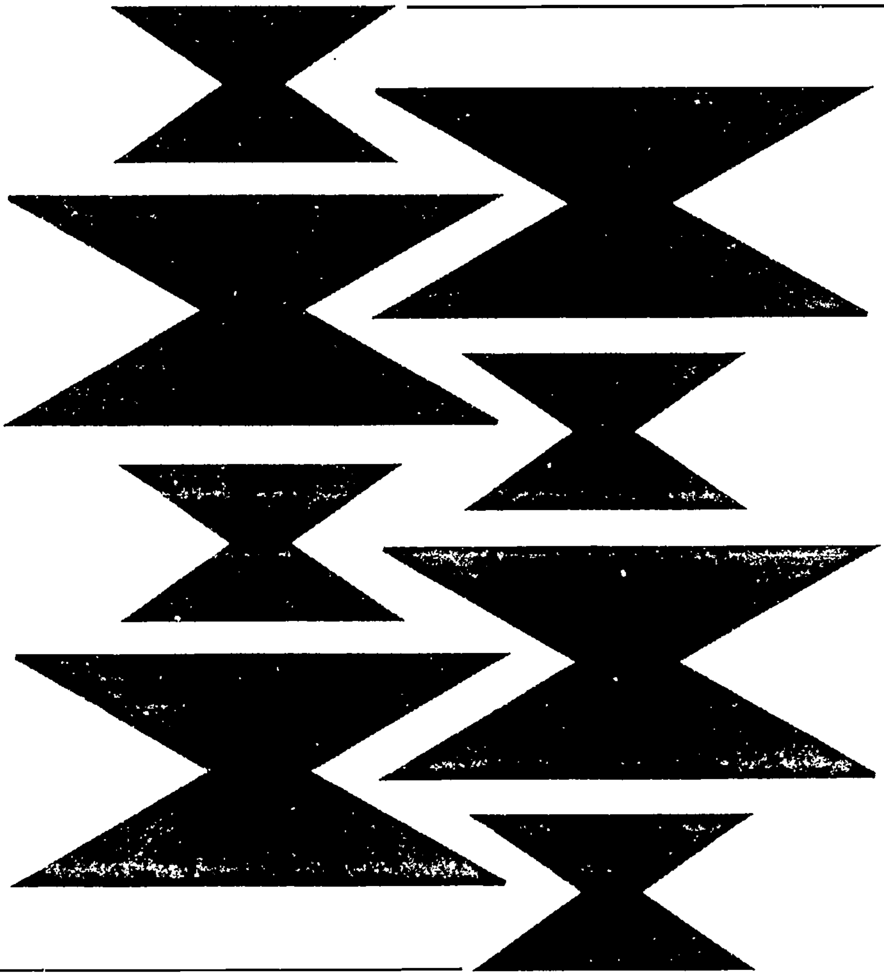
Introduction and Purpose of the Study



CHAPTER I

Introduction and Purpose of the Study

Objectives

1. To delineate the scope and purpose of the study, highlighting a new paradigm for all participants in rehabilitation, including practitioner, researcher, and consumer of services
2. To identify a common ground in which all participants are assured maximum participation in the rehabilitation service delivery system
3. To identify relevant and historical antecedents that lay the foundation for participatory action in rehabilitation

Summary

The concept of consumer involvement in rehabilitation is not a new issue. In the 1960's people with disabilities began to speak out for more participation in decision and policymaking, as well as more accountability in rehabilitation. Since then, the growth of consumer coalitions and active political participation among persons with disabilities has continued to escalate. In October of 1992, Congress extended, and the President signed, the Rehabilitation Act Amendments (P.L. 102-569) which provide the legal basis to give more control to consumers of rehabilitation services.

The focus of this document is to a) show how persons with disabilities can better participate in their rehabilitation programs, b) lay the foundation for shifting attitudes about this process, and c) outline how professionals in research and practice can find greater success, resources, and understanding of rehabilitation issues through collaboration with all concerned.

Discussion

A Shift in Thinking

Everyone has a stake in the success of rehabilitation as well as the quality of services the program provides. Since the focus of rehabilitation is on the quality of life of the people it serves, it is imperative that researchers and practitioners become sensitive to the needs of people with disabilities. The key, therefore, to continued success of rehabilitation efforts is the involvement and participation of researchers, practitioners and consumers.

The focus of this study is on the use of a team approach in order to increase consumer involvement in rehabilitation. Consumers of services make a valuable contribution to rehabilitation, and as stakeholders in the process, should have the power to actively participate in the process that will eventually impact their lives. The IRI Study Group has attempted to provide information that can be used by rehabilitation agencies and organizations to increase participation of all stakeholders.

The traditional paradigm for rehabilitation has been the medical model in which problems of clients were defined and some action or treatment prescribed to fix the problems. This model could also apply to the researcher-practitioner paradigm that now exists in the area of rehabilitation research.

If people with disabilities are to be involved in all aspects of the rehabilitation process, they must be equal partners, thus requiring a new paradigm. William H. Graves, former Director of the National Institute on Disability and Rehabilitation Research, shared his concept of the future of rehabilitation. He called it Participatory Action Research. In remarks to the National Association of Rehabilitation Research Directors, Graves (1991) presents a new paradigm in which individuals with disabilities are actively engaged in the quest for information, and participate as partners in the process of gaining knowledge. This participatory action concept should apply not only to researchers but to other major players in rehabilitation—the counselors and consumers. There is no need for change in commitment to rehabilitation. The need is to modify the present system to provide for greater collaboration among the participants.

Several factors influence this new direction. Primarily, the enactment of the American with Disabilities Act (ADA, P.L. 101-356, 1990) casts a whole new light on consumer involvement and participation. The reauthorization of the Rehabilitation Act (P.L. 102-569, 1992) and the state grant programs for Technology-Related Assistance for Individuals with Disabilities Act (P.L. 100-407, 1988), commonly referred to as the "Tech Act," are other significant pieces of legislation.

Under the reauthorization of the Rehabilitation Act, the strongest component is the establishment of Rehabilitation Advisory Councils and Oversight Committees on Independent Living Issues at both the state and federal levels. This new collaboration places a high value on the participatory process. The intent is to clearly provide persons with disabilities the opportunity to have major influences on state rehabilitation programs and independent living services. Similarly, and more directly, the Tech Act establishes state grant programs directly responsive to consumer needs for assistive technology and devices, and involves a broad community-based approach to identify needs.

Recently, a congress of people with disabilities in Michigan completed an annual meeting called "The Event." The purpose of the meeting was to develop a platform upon which to organize political strategy. Topics included transportation, housing, health care, income maintenance, independent living services, and personal assistance (Event, 1992). A review of literature in rehabilitation quickly indicates that these topics have been targets for research and practice for many years. It is obvious that these issues continue to be of concern among people with disabilities because they are still unresolved. It becomes clear that existing programs have not addressed these issues to the satisfaction of the target populations. Perhaps the problem lies not in the inability of people with disabilities to successfully integrate themselves into the community, but in the inability of the system to recognize and respond appropriately to the needs of consumers. This transition in attitude and practice moves from the traditional medically defined model toward viewing the consumer as a valuable contributor, having a significant and active role to play.

The shift in our thinking must focus on a new paradigm, according to Condeluci (1991). The problem of disability, is defined, not in terms of what is wrong with the person, but from the context of limited supports to allow the person with a disability the opportunity to fully participate (Condeluci, 1991, p. 90). In order to accomplish this objective, the rehabilitation system must be adjusted so that all individuals can access the services they need. The support that is needed comes from this shift in attitude and response to the system.

Need for the Study

Consumer Involvement has been a topic of interest for many years. The Second Institute on Rehabilitation Issues (IRI), addressed this topic in 1975 in a document entitled, Consumer Involvement: Rehabilitation Issues. Another IRI study, Client Involvement: Partnerships in the Vocational Rehabilitation Process, was completed in 1988, some 13 years later.

During and following the Vietnam War there was an upsurge of self-advocacy among persons with disabilities in regard to housing, employment, and training. Since that time there has been a progression of self-advocacy among persons with disabilities. A number of rehabilitation research and training centers responded to this pressing issue in the 1970's and 80's, bringing about more program accountability through the use of planning and evaluation.

This study is a direct result of the demand by consumers to have more voice and control in their programs of service. The status-quo is no longer acceptable in improving the quality of life for people with disabilities, as indicated by the demand for better communication among the major players. This manual is intended to delineate some of the strategies needed to facilitate this interaction. People with disabilities increasingly express their need to be more involved in the planning and implementation of rehabilitation research and practice. If it is true that a major objective of rehabilitation is to integrate the person with a disability into the community to the fullest extent possible, how successful has rehabilitation really been? Individuals with disabilities are voicing more objections to being the object of research studies, and disenfranchised from the very effort that leads them to community integration. Agencies are faced with limited funds and other resources; therefore, they must collectively explore ways to collaborate while addressing the issues of rehabilitation. The quality of these outcomes will be greater if all players, including stakeholders, participate in the process.

Researchers, service providers, and service recipients can relate to the feeling of being ignored, isolated, or excluded from some part or all of the process. As an example, researchers conduct studies of counselor attitudes of clients, or the correlation of caseload size with client outcomes, with the certainty that a majority of counselors, and vocational rehabilitation administrators will not read their findings. Since they receive little, or no, feedback it perpetuates the myth that they have no real value. It will be no easy task to change. There is no immediate reward for doing a job differently, or for people in an organization to shift their methods to a new paradigm.

This study attempts to find a common ground by defining terms and exploring concepts, as well as covering in some degree the historical and philosophical background which has brought this issue to the forefront. An important element of this manual is an examination of current systems of rehabilitation research and practice, and the relationship of these to consumer involvement and participation. The chapters in the monograph help identify terms and concepts needed to shift thinking, define the historical genesis of "consumerism" (See Chapter II for definitions) in rehabilitation; provide a description of the current factors in research and practice as seen from the service users viewpoint; and describe innovative applications for participatory action. In addition, the report describes some current approaches, and provides readers with some future directions and recommendations for meeting on a "common ground."

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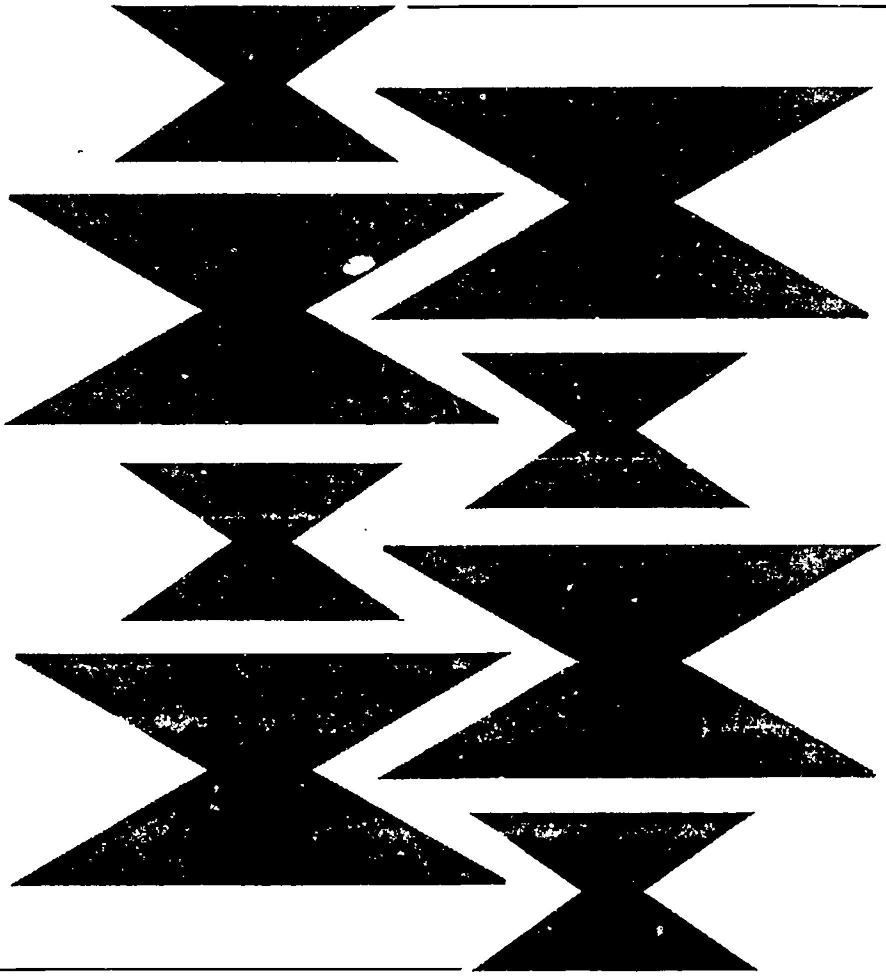
Definitions: A Word about Language



CHAPTER II

Definitions: A Word about Language

Words are the legs of the mind
They bear it about, carry it from
point to point, bed it down at night
and out of marsh and mists.

Eder (1979)

Objectives

1. To facilitate an accurate interpretation of key words, phases, and concepts used throughout this text

2. To serve as a basis for standardizing terms and for improving communication among researchers, practitioners, and consumers

Summary

This IRI Study addresses the linking of the rehabilitation researcher, the practitioner, and the consumer in achieving a common ground in the development, implementation, and realistic application of rehabilitation research results. To this end, this chapter provides an explanation of the keywords and terms used in this IRI Study on Consumer Involvement in Rehabilitation Research and Practice.

Discussion

What's in a word? Words, like people, have both a personality and a history—rooted in the past, but stretching toward the future (Garrison, 1965). Often taking on new meanings, words are used to love, to quarrel, to propitiate, and to pardon, to rebuke, to console, to intercede and to arouse. A good analogy is not that of an insect undergoing metamorphosis, but that of a tree throwing out branches (Lewis, 1960). Words and language convey attitudes or points of view that shape our beliefs, prejudices, ideas, and aspirations. For instance, the word "handicap" has been widely used as an alternative to the word "disability." Originally viewed as a neutral term, much in the same manner as a golf handicap, use of the word "handicap" began in England in the 15th and 16th centuries to refer to individuals with disabilities. In England, people with disabilities would sometimes stand, sit, or lie at a street corner, cap in hand, begging. This led to the term "hand cappers" and ultimately "handicap," thus reflecting how the same word can, over time, come to have different perceived connotations (Rice & Thayer, 1990).

Words, therefore, are potent instruments for communication. Because different people attach very different meanings to the same word, the possibilities for misunderstandings are infinite (Corthell & Von Boskirk, 1988). With the use of technical language, the semantic variations increase tenfold. The phrase "consumer involvement," for example, may appear straightfoward in meaning, while in actuality it may connote different meanings to each reader.

To the researcher, consumer involvement may be having a person with a disability try some new or innovative techniques. To the practitioner, the phrase may mean involvement of the client in development of the Individualized Written Rehabilitation Program. To the individual with a disability it may mean the ability to direct research to a problem involving day-to-day life activities. It becomes apparent that all players—researchers, practitioners, and consumers—must have the same understanding of the term "consumer involvement" if they are to communicate effectively in regard to it.

Long recognized as a major skill and influence in the rehabilitation partnership, communication is a staple of success in any business and is one of the strongest connecting links between individuals (Corthell & Von Boskirk, 1988). Communication is vital to the rehabilitation process, and efforts at reducing differences must be exercised if a common perspective and partnership are to be achieved.

With this understanding and with the objective of "closing the gap", the Prime Study Group offers the following definitions of key words and concepts found throughout this study.

Common ground. The foundation or basis upon which all individuals are searching for a new or better reality regarding need, disability, possibility, capacity or concern.

Connectivity. The linking of a problem, the research, and the solution to achieve a common ground in which all players can truly complement each other's needs, skills, and contributions.

Consumer. Individuals with disabilities and persons significantly involved in improving the quality of life of such individuals outside the "systems of care." This term includes the person directly affected by the disability as well as others indirectly affected by the disability, such as significant family members, friends, or employers of the person with a disability.

Consumerism/Consumer involvement. A process of systematic and intentional interaction on the part of all parties who provide a unique perspective to the relationship on issues that ultimately impact the recipient of services, including persons with disabilities and their significant family members, providers of services, policymakers, organizations and groups.

Disability. Any restriction or functional impairment that results in an individual's inability to perform activities within a customary range for individuals of the same age, education, and cultural background

Empowerment. A holistic approach to rehabilitation embracing the philosophy that people with disabilities have the right to control their own lives; to integrate as active, productive and respected members of society; and to have equal access to opportunities to obtain their maximum potential.

Individuals/Organizations who are affected by disability. Persons with disabilities and others who have personal contact with them on a day-to-day basis, such as direct care providers and family members.

Individuals/Organizations not affected by disability. Other significant family members, organizations, agencies, and businesses who are impacted by a large number of individuals with disabilities.

Paradigm. Suited as an example, model, or pattern that sets the tone for current and future movement (Condeluci, 1991).

Participatory action research. Applied rehabilitation research that includes people with disabilities, their families, service providers, scholars, policymakers, and/or other members of the community in the quest for information from the initial conception of the idea through implementation and evaluation of its impact.

Practice. The full range of professionals and paraprofessionals who work in the field of rehabilitation by affecting, causing, controlling, and delivering "systems" of care and rehabilitation, including administrators.

Rehabilitation. To provide persons with disabilities with the resources to move from a position of dependency in their communities to positions of self-reliance and independence in a community of their choice.

Research. Systematic and scientific inquiry for the purpose of finding direct answers to questions, developing new techniques, eliminating errors in practice, achieving new knowledge, and contributing to theory which involves the following interrelated functional stages:

1. formulation of the problem
2. planning
3. acquisition of data
4. analysis and reporting
5. synthesis and dissemination
6. transfer of application

Applied Research. Research to improve a product or a process by testing theoretical concepts in actual problem situations (Best, 1981).

Rehabilitation Research. Diligent inquiry, investigation, or examination to seek factual information that can offer solutions to disability issues in order to facilitate and create maximum opportunities for individuals with disabilities and assist them in assuming control of their personal lives.

Conclusions and Implications

The development of a true partnership among all the stakeholders in rehabilitation depends, to a large extent, upon open and honest communication. If all parties are to be involved on an equal basis, nothing is more vital than assurance that everyone is on the same "wave length" and that words used are understood and interpreted in a similar fashion by all. This is a very difficult achievement since words mean different things to different people and the chances for misunderstandings are great. Checking back on communication by the involved parties to be sure that everyone is together is an absolute necessity. The definitions presented in this chapter should be a step in the right direction.

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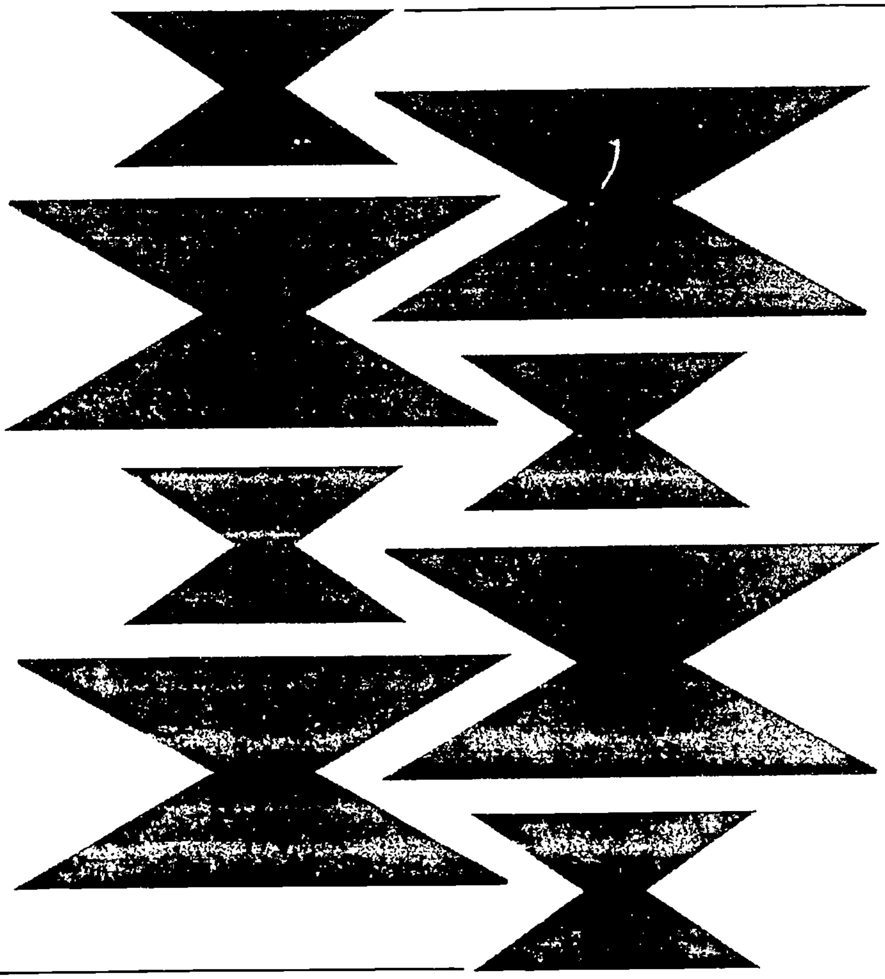
Historical and Philosophical Background of Consumer Involvement



CHAPTER III

Historical and Philosophical Background of Consumer Involvement

Objectives

1. To provide a historical and philosophical perspective of the disability rights movement with respect to social attitudes and consumer participation in research and practice

2. To discuss consumerism from a historical perspective and provide current examples of consumer involvement in industry

3. To show the impact of the disability rights movement in connecting researchers, consumers, and practitioners

Summary

Sweeping changes in federal legislation over the past decade require meaningful participation of consumers in planning, implementing, and evaluating services. These changes were initiated by the independent living movement in the 1960's, and reflect marked changes in social attitudes toward consumers. Examples from industry demonstrate how productive consumers drive successful product research, design, development, and marketing. In rehabilitation, this will happen only when researchers and practitioners understand and acknowledge the value of consumers as equal partners. This chapter presents these themes in the context of the consumer movement as an important force that will have, or should have a tremendous impact on rehabilitation research and practice

Discussion

The History of Rehabilitation and Social Attitudes Toward Consumer Participation

Much has been written about the value and need for consumer participation in the rehabilitation literature. In reviewing the literature, consumer involvement was identified nearly twenty years ago as "not a new concept." (Rice & Orsburn, 1975). The question remains as to why this value is not yet in widespread practice. The notion of full inclusion in school, work, and community settings is now widely accepted by leaders in the field; but as a force that drives rehabilitation research and practice, it has yet to be fully implemented.

This chapter will present information from many sources to help readers understand the disability rights movement as an indicator of change in social attitudes toward consumers, and as the primary force that will impact future legislation, rehabilitation research, and practice. The chapter draws examples from successes and failures in the private sector to support the argument for full inclusion of consumers in research and practice. These examples will show that good products are designed only when consumers have been substantially involved throughout the research process. Instead of viewing consumers from a traditional disability perspective (i.e., recipients), rehabilitation researchers and practitioners must pro-actively view consumers as equal partners and primary stakeholders. This chapter does not propose any one method for consumer participation but points to the need to develop processes for inclusion as an ethical and practical concern. The over-arching theme of inclusion must become a universal, unchanging principle driving research and practice, even though processes for inclusion will undoubtedly change. Without acknowledgment of the need for consumer involvement in research and practice the benefits to consumers will be nominal.

The History of Rehabilitation: A Reflection of Social Attitudes Toward Persons with Disabilities

From earliest recorded history through the present, rehabilitation literature and legislation reflect the evolution of social attitudes toward people with disabilities. Until recently, people with disabilities have been disenfranchised because society viewed them as sinners, sick, poor, and dependent. An examination of the literature concerning rehabilitation laws and services shows clear evolution of social attitudes. A close examination of the expansion of rehabilitation services in America demonstrates how programs with very specific goals, specific disabilities and age groups are evolving to very general, wide-ranging programs for almost all types of disabilities and age groups (Jenkins, 1987). More recent legislation and programs are focusing on persons with disabilities as whole persons with rights to equal participation in various settings across their lifetimes, as opposed to persons with defects to be corrected by experts.

A good understanding of the evolution of attitudes, legislation and services can be gained by looking at key "events" from Biblical times through today (See Table 1). Some information from the Seventeenth Institute on Rehabilitation Issues, Vocational Rehabilitation Services in Independent Living Centers (Rice & Thayer, 1990) was used and amplified in this chronology. Daniels (1990, 1992) referred to these as paradigm shifts in an expanding social view of persons with disabilities as contributors and customers rather than as recipients of services.

Jenkins stated that "the history of legislation reflects in a microcosm, a picture of the development of social attitudes in America, as well as the development of the philosophy of rehabilitation and the expansion of the rehabilitation services through the years" (1987, p. 4). Such development has proceeded from such programs as shown above with very specific goals to ones with a view of the whole person across settings. This discussion will provide a brief description of some of the key laws and subsequent programs that illustrate the movement of persons with disabilities toward full inclusion and empowerment

The first federal law promoting rehabilitation legislation was the Smith-Sears Act of 1918 (P.L. 65-178). Rubin and Roessler (1987) refer to this Act as the Soldier's Rehabilitation Act of 1918. This Act provided vocational training or re-training and placement for soldiers disabled during World War I. Two years later, the Civilian Rehabilitation Act, modeled after the Soldiers Rehabilitation Act was passed to extend this program to civilians. In 1943, the Bardon-Lafolette Act (P.L. 78-113) expanded the concept of "disability" by making persons with mental illness as well as mental retardation eligible for services. The law also expanded the definition of "vocational rehabilitation services" by adding physical restoration to the list of authorized services. The next major rehabilitation legislation was the Vocational Rehabilitation Amendments of 1954 (P.L. 83-565). This legislation was the first to provide Federal funds for training rehabilitation personnel, for establishing rehabilitation research and demonstration projects, and establishing facilities. This marks an important point in both the recognition of rehabilitation as a profession as well as the emergence of a stronger medical model orientation (e.g., experts fixing deficits).

Consumers as Equal Citizens with Equal Rights: Moving from the Medical Model to a Participatory Model

The Rehabilitation Act of 1973 (P.L. 93-112) brought sweeping changes to the field. First, it placed emphasis on serving persons with severe disabilities. Second, it was the

Table 1. A Chronology of Paradigms, Laws, and Social Attitudes

YEAR	KEY ATTITUDES/ IMPACTS	LITERATURE/ LEGISLATION	PARADIGM
1446 BC	Disease inflicted by Satan (Job 2:7) or by God (Mic. 6:13); Sinful, Uncleanliness, Aversion (Wright, 1980, p. 119)	Old Testament	Exclusion
Before 70 AD	Jesus casted out demons and unclean spirits (Matt. 9:32; Matt. 10:1)	New Testament	Healing
1200 BC - early 20th Century	Charity, Benevolence, Asylum, Humanitarianism	Elizabethan Poor Law, 1601	Paternalism
1918	Rehabilitation for soldiers; not persons with disabilities as whole	Soldier Rehabilitation (Smith-Sears) Act; Public Law 65-178	Vocational
1920	Recognition of rehabilitation needs of civilians, not just soldiers	Civilian Rehabilitation (Smith-Fess) Act (Rubin & Roessler, 1987)	Vocational
1943	Mental Illness and Mental Retardation and Physical Restoration are recognized	Vocational Rehabilitation Act Amendments (Barden-LaFollette Act) Public Law 78-113 (Wright, 1980, p. 139)	Restoration & Expanding Definitions of Disability
1954	Experts are needed along with research to develop expertise; Special places (i.e., facilities) are needed to fix special people. (Daniels, 1992 Presentation at RESNA All States Meeting)	Vocational Rehabilitation Act Amend-ments (Hill-Burton Act) Public Law 83-565 (Wright, 1980, pp. 141-142)	Deficits Fixed by Experts
1973	Persons with severe disabilities need services	Rehabilitation Act of 1973	Civil Rights Inclusion
1978	Quality of life is a right	Amendments to the Rehabilitation Act of 1978, Title VII, Independent Living & Developmental Disabilities Amendments (Public Law 95-602)	Whole person Self-determination
1984	Supported employment services for people thought unemployable	Developmental Disabilities Act	Inclusion in workplace
1984	Participation of consumers as evaluators of independent living services	Comprehensive Evaluation of Independent Living Services	Consumer-responsiveness
1986	More focus on independent living, on severe disabilities, provision of rehabilitation engineering services, and elimination of barriers	Amendments to the Rehabilitation Act of 1973	Whole person across settings
1988	Technology is the great equalizer	Technology-related Assistance for Individuals With Disabilities Act (Public Law 100-407)	Technology Interventions for Inclusion – All ages
1990	Equal access to employment, public facilities, transportation, and telecommunications	Americans with Disabilities Act	Empowerment: Rights and Legal Remedies
1992	It shall be presumed that an individual can benefit in terms of an employment outcome from vocational rehabilitation services (presumptive employability)	Rehabilitation Act Amendments of 1992	Full inclusion

first act to address the notion of equal access of people with disabilities through the removal of architectural, employment, and transportation barriers. Third, Title V of this law was the first to address the civil rights of individuals with disabilities. Five years later Amendments (P.L. 95-602) to the Rehabilitation Act served to establish independent living as a legitimate goal of the rehabilitation process which signaled the expanded view of the person, as a whole person, with needs that cut across the bureaucracy.

Culminating with the Americans with Disabilities Act of 1990 the disability rights movement should be viewed as an evolution from early history through the present, and as a struggle toward full inclusion and independence. During the past two decades, the struggle has centered on emergence from the medical model, a paternalistic approach to the delivery of rehabilitation that focuses on symptoms of recipients to be diagnosed and prescribed by experts. The Independent Living Movement is viewed as an important step in the disability rights movement. The Seventeenth IRI, Vocational Rehabilitation Services in Independent Living Centers (Rice & Thayer, 1990), defined this movement as:

> The civil rights movement for people with disabilities that promotes the philosophy that people with disabilities have the right to control their own lives and have access to the same options as people without disabilities. This philosophy is based upon the concepts of disability esteem and personal value, consumer control and self-determination, self-help and peer support, and political activism. (pp. 17)

Not until the 1970's was this view of consumers as equal citizens voiced. The civil rights movement of other minority groups (e.g., blacks, women) most certainly fueled the disability rights movement. These developments along with rapid innovations in medicine and technology made for a climate ripe for hearing the voice of consumers. During this time, also, consumer advocacy groups began to spring up in communities across the country with a focus on self-help, community care alternatives, and improvement on the quality of life of children and adults with disabilities. The disability rights movement was finding a political base in the communities of this country. As testimony in 1976, the American Coalition of Citizens with Disabilities was formed as the first organization to include consumers from all the states and across disabilities (Rice & Thayer, 1990). This group has been instrumental in the passage of recent legislation, including the Technology-Related Assistance for Individuals with Disabilities Act (1988, P.L. 100-407) and the Americans with Disabilities Act (1990, P.L. 101-356). Consumer participation was put into practice by the research and training centers in the early 1970's before the Rehabilitation Act of 1973 and the 1974 Amendments. Fenton (1977) reported in the Informer that the research and training centers had recognized the value of meaningful consumer participation to tie research to the needs of consumers, assure the research and training activities are responsive to the goal of the Rehabilitation Services Administration (RSA) and to ensure dissemination of research findings to the appropriate constituencies. Research and training center workshops, training manuals, and reports under score the emphasis placed on consumer involvement. This emphasis inevitably resulted in discussion about defining "consumers" as meaningful informers, not token representatives. The prerequisites of consumers to be selected for involvement in research and training center projects included:

- involvement in a constituency
- users of research
- knowledgeable

According to Remmes (1978), the questions to be ask about consumer participation include:

- Who do we need?
- Why do we need them?
- What can they do for us?
- What can we do for them?

Consumer participation at the RT Centers is done by involving consumers on Advisory Councils and through the employment of staff and trainers with disabilities. The Advisory Council model for participation was illustrated in the 1976 Annual Proceedings of the RT Centers and is shown in Figure 1 (Fay, 1976).

The Technology-Related Assistance for Individuals with Disabilities Act of 1988 (P.L. 100-356) was another landmark law. It was the first piece of legislation that clearly cuts across all traditional boundaries of age, discrimination, and disability. It views each child, adult, and older adult as entitled to equal access to opportunities that can be achieved through available assistive devices and services. The Technology Act provides states with grants to achieve systems change so that these devices and services will, in fact, be available to traditionally underserved groups. It is one of the first laws that repeatedly drives home a mandate for consumer-responsive services and significant inclusion of persons with disabilities in planning, implementing and evaluating progress toward systems change. It is a law that creates an environment for participatory research in finding "best" practices for such changes.

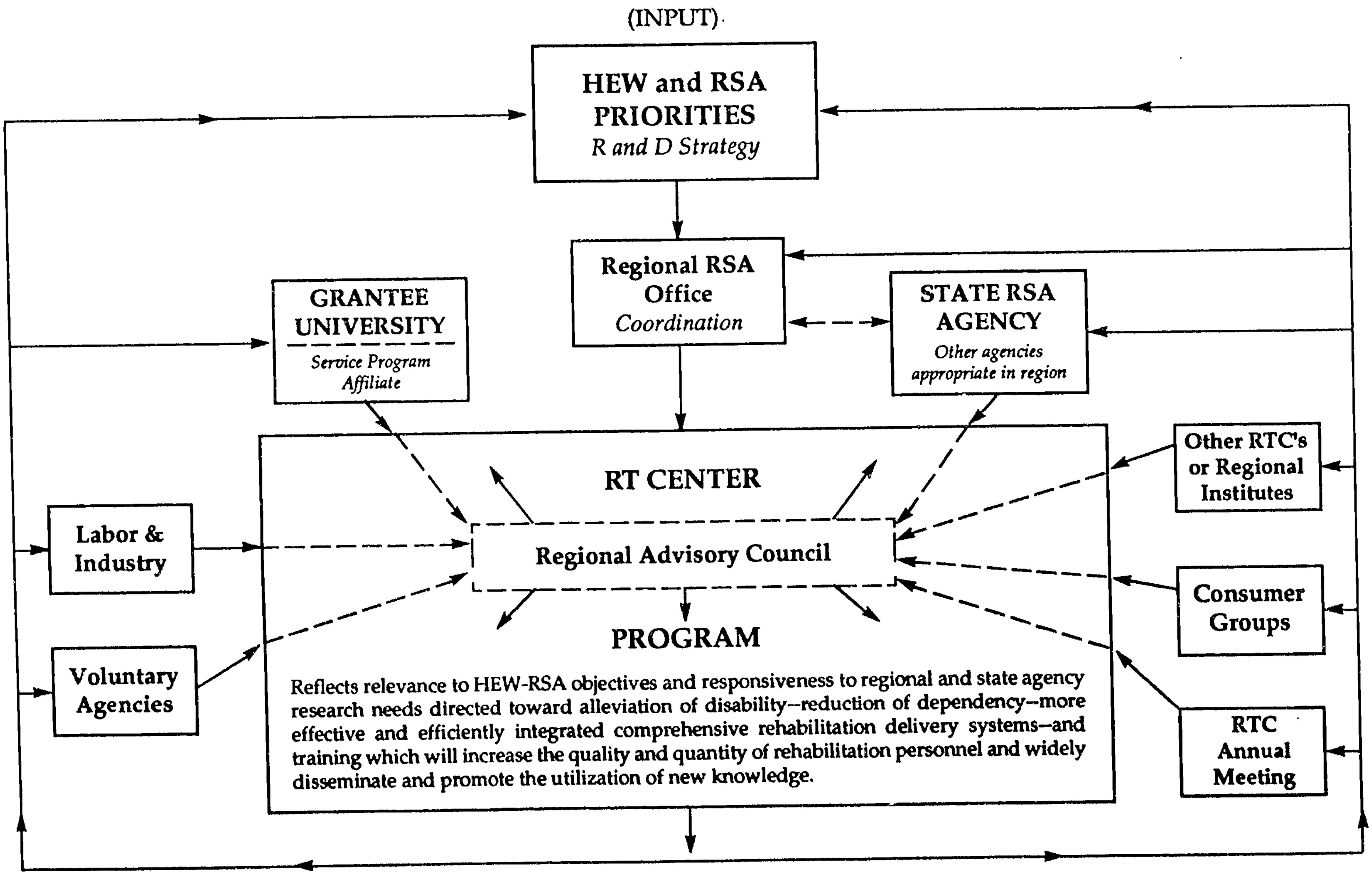
The Americans with Disabilities Act (P.L. 101-356, 1990) was signed into law by former President George Bush on July 26, 1990. With its five sections, it guarantees the rights of persons with disabilities equal access to employment, public facilities, transportation, and telecommunications. The full impact of this law has yet to be seen.

The Rehabilitation Act Amendments of 1992 (P.L. 102-569) signal a new era for persons with disabilities served by the public rehabilitation program. The Amendments mandate presumptive employability which means applicants will be presumed to be employable unless proven otherwise. Philosophically, the Amendments are evidence of the movement toward full inclusion of persons with more severe disabilities by presuming that they can benefit from services designed to help them achieve employment.

It is important to note that, as each of these laws and social attitudes emerged, they were viewed at the time as revolutionary. Later, revolutionary ideas, approaches and institutions tend to become calcified; changing needs then drive the emergence of new ideas. For example, the notion of sheltered workshops was once a revolutionary idea and a solution to the need for employment of people with severe disabilities who, without the benefits of today's technology and automation, could not work competitively. Today, supported employment is a revolutionary solution to include these workers, often by using assistive devices and other services to support employment. As such supported employment is a revolutionary concept in rehabilitation. Traditional rehabilitation services used to end at employment but supported employment services begin at employment. It is important to understand these developments as a part of the process in a changing social, economic, and technological world. This rational view can promote collaboration among consumers, practitioners, and researchers rather than antagonism through oppression and exclusion.

RT CENTER PROGRAM DEVELOPMENT

RTC Strategy



Reflects relevance to HEW-RSA objectives and responsiveness to regional and state agency research needs directed toward alleviation of disability--reduction of dependency--more effective and efficiently integrated comprehensive rehabilitation delivery systems--and training which will increase the quality and quantity of rehabilitation personnel and widely disseminate and promote the utilization of new knowledge.

Drawing from Consumerism in the Private Sector: A Participatory Marketing Model

This section gives an historical view of consumerism in America. It also describes a strategic, market-driven model successfully used in industry, and draws from examples in the private sector.

America was founded on consumerism from the grassroots. The American Revolution was a conspiratorial economic revolt against tyranny of the English throne. According to Naisbitt (1982), individuals who are affected by decisions should be a part of those decisions. In the private sector, the need to involve consumers is a well-understood foundation of sound business practice among the best companies. It is crucial to understand the economic rationale underlying this market-driven, or what Naisbitt (1982) calls "participatory" approach. Consumers are buyers of goods and services; therefore, goods and services must be tailored to their unique needs. A failure to do this may lead to failure of the company and tremendous economic loss to its stakeholders.

Within the framework of traditional public rehabilitation practices and research, consumers have not had decision-making roles. Lack of empowering roles has led to militancy and radical ideas such as the voucher system, a way of empowering consumers with both economic and decision-making roles. Equal participation in policymaking, management, focus groups, and program evaluation is currently the primary method used to gather consumer input into decisions about rehabilitation services. However, consumer input is meaningful only when explicitly gathered, evaluated and used to improve services.

In both rehabilitation and industry, using a marketing, or participatory model means:

- Needs are "desires" or "wants" stated by consumers.
- The organization considers these expressed needs with respect to its resources.
- Consumer needs and use of services are seen as related.
- Consumers prioritize their needs.

In this context, needs assessment is defined as:

> A process for identifying and choosing among service options that a target population values and would therefore, find worthwhile and use (Rehabilitation Needs, 1, 1991, p. 46).

This model involves consumers from the beginning. It is likely to result in customer satisfaction, an indicator of program success. (Rehabilitation Needs, 1, 1991, p. 47).

Naisbitt and Aburdene (1985) stated that, if industry does not heed what customers are demanding (e.g., a voice in decisions that affect them), they will become more militant in the next decade. The passage of the ADA is testimony to militancy and the demand for inclusion of people with disabilities. Within this context, accountability of services funded by the public means that services must be competitive in meeting real market needs. These needs can only be determined by listening to customers and by developing "best practices" through relevant research driven by these needs. Listening and reacting to customer needs demands a mindset that:

1) embraces the notion of change and adaptive organizations;

2) recognizes that good solutions today will be outworn and ridiculed tomorrow;

3) pro-actively encourages incubation and testing of innovation, even while knowing that the majority of innovations may not yield results (Drucker, 1986);

4) resists the status-quo; and

5) encourages input from a cross-section of customers and networks across lines (Peters, 1987; Naisbitt, 1982).

If public rehabilitation agencies and research initiatives fail to respond to real needs the demise or restructuring of rehabilitation as it is today can be expected. One need only to look at the economy and the fierce competition for funds to recognize the need for absolute qualitative data and customer endorsement of programs to justify federal and state expenditures.

Lessons from the Private Sector: Some Successes and Failures

Industry provides excellent examples of successes resulting from participatory corporate practices. A great deal can also be learned from failures that occurred when businesses failed to understand their market. A few of these success and failures are related here to inspire the use of participatory practices.

According to Peters and Austin (1986), a major reason for the success of Japanese businesses has been direct contact between product engineers and customers. The Sony Walkman portable cassette player was the result of direct contact between a Sony engineer and roller skaters. Traditionally, marketing "experts" have been the middlemen between engineers and customers. This example suggests that, to get better rehabilitation products and services, researchers, in formulating research ideas, need to go to the customers (e.g., practitioners and consumers).

Everyone is familiar with the Coca-Cola story. Marketing experts predicted that the new Coke would increase profits by stealing Pepsi-Cola customers. The new Coke, a sweeter concoction similar to Pepsi, had been predominantly chosen in taste tests. Market experts failed to consider the market value of nostalgia. Five days after the new product was announced, the company was receiving over 1,000 calls a day from irate customers (Oliver, 1987). Customers valued its tradition, its place in their history, and its familiar taste more than they valued the newer concoction. Market analysis considered only one dimension of customer satisfaction—taste.

A Toy Manufacturer was praised by Peters (1986), for its exemplary practice of soliciting recommendations and listening to its primary customers, children. The company recruits and pays children to play with toys being considered for introduction to its product line. Any toy that does not pass criteria established by children is not produced. In one case cited by Peters and Austin (1986), potentially lucrative negotiations with a large American retailer were ended when the retailer refused to buy the entire line of products. In this case, the company's market experts (children) had recommended that the entire line be sold without exception.

These examples illustrate the participatory market model. It values consumer participation as an integral component of the design, delivery, and evaluation of products and services. Although there is evidence of increasing use of this model in rehabilitation needs assessment (Rehabilitation Needs, 1, p. 47), it is not yet widely practiced as an integral component of research, policy development, and evaluation of services.

Conclusions

A Research Network for Researchers, Consumers and Practitioners

This chapter has highlighted the disability rights movements as the single most important impact on rehabilitation practice and research today. Consumers have legislated their voices. Political power is evident; economic power is at the threshold. Rehabilitation services, as designed by researchers and as practiced by practitioners, must respond by implementing inclusion from the beginning as a cornerstone of best practices. With this recognition, comes empowerment of systems, and dynamic research that maximizes the contributions of all participants.

Some implications are listed below:

1. The history of rehabilitation laws and prevailing attitudes toward persons with disabilities has evolved toward a paradigm of participation in the fullest sense, or empowerment.
2. America is philosophically rooted in a vision of grassroots consumerism.
3. Both public and private enterprise lost sight of vision of consumerism and are undergoing rediscovery.
4. Rediscovery of consumerism is reflected in social activism, and civil and consumer rights movements.
5. Change will be constant, and only adaptive organizations will survive.
6. Adaptive organizations today are ones where research development is tied directly to customer needs.
7. Linking customer needs to research and practical applications must drive the formulation of networks of researchers, practitioners, and customers.
8. Quality, cost-containment, and satisfied customers are by-products of participatory practices.

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A Common Ground

CHAPTER IV

A Common Ground

Objectives

1. To present an expanded view of the players in rehabilitation research and practice
2. To describe the influences within the environment in which practitioners, researchers, and consumers exist, noting their differences and similarities
3. To define what each player has that is unique and contributing
4. To identify implications, analyze, and make recommendations

Summary

It is clear that in governmental and human services there are a multiplicity of audiences or interested participants. In the delivery of rehabilitation and independent living services there are companion interests found in the welfare system, community mental health programs, legislatures, etc. All are interested in the process as it affects their constituencies. Customers (clients or employers) may have a different interest. When examined in its whole, there are a variety of players involved in the process. In order for all of them to have equal impact there must be a singular vision to best serve people with disabilities, a common understanding of the process beyond the internal dynamics of state vocational rehabilitation agencies or university-based rehabilitation research programs. Researchers, practitioners, and people with disabilities must collaborate in the development of a marketing play that focuses on customer satisfaction and assures that a) people with disabilities are involved in the plan, b) people with disabilities receive the services they expect, and c) employers get the best possible employees to meet their needs. A more thorough understanding of the antecedents of this approach can be found in the work by Berkowitz (1987) where the failure of past policies has in fact pointed the direction for the current changes in rehabilitation efforts.

Sweeping changes in federal legislation over the past decade require meaningful participation of consumers in planning, implementing, and evaluating services. paradigm shifts in an expanding social view of persons with disabilities as contributors and customers, rather than recipients of services, are now the mainstay of research and practice in rehabilitation.

Discussion

Participation in the Research Process

"Players" are the people who are involved in all aspects of the research process from inception of the need for research, through the technical phases of research, and into translation of the findings into practice. Players are not members of some collective or some committee too often brought in to make sure that "research" and "practice" are socially appropriate or popularly supportable. Players are the people who promote things that work, including things which may not appeal to "popular" perceptions of what is appropriate.

Consumers. "Consumers" in this document refers to those people who will be most directly affected by research and by a practice that might derive from the research. Consumers include the person directly affected by disability (a client), and people indirectly affected (significant family members, friends, or employers of the person with a disability). They are the individuals with disabilities and the people who are significantly involved in improving the quality of life of such individuals outside the "systems of care."

Consumers bring sensitivity, history, and experience, to the disability issue. Consumer involvement is a valued resource in the research, development, and practice effort.

Practitioners. Practitioners are a broad category of professionals and paraprofessionals involved in planning and delivering the "systems" of care and rehabilitation. Practitioners are the professional rehabilitation counselors, peer counselors, rehabilitation administrators, public policy advocates, social or welfare service bureaucrats, case managers, job coaches, trainers, proponents and the opponents of seemingly needed change, teachers of consumers, and teachers of other practitioners.

In real terms, practitioners strongly influence the adoption or rejection of innovation. They possess technical knowledge, skills, and experience about what has been effective and ineffective practices for people with disabilities. When we speak of practitioner involvement, we are not speaking narrowly of one group of people in a service delivery unit or program. Rather, we are speaking of the people who can advocate, implement, or access resources to put into place innovation that may reduce the impact of disability.

Researchers. Researchers are the people with meaningful training and experience in philosophy, theory, and technology of research processes, and who are inherently involved in finding or creating "realities" that can be replicated. Above all, researchers are concerned with acquiring new knowledge, eliminating myths, and achieving functionally valid improvements in the rehabilitation process.

While researchers often have answers to questions posed by practitioners and consumers, researchers tend to be cautious and conditional in supplying those answers. Steeped in the tradition of scientific inquiry, researchers are of greatest value when they impose order and quality control into the search for innovations and solutions.

The Consumer Focus

Consumers are more likely to invest and participate in services when they believe the outcomes will have some impact on their lives. The greater their involvement and control over the circumstances, the greater the investment. The relationship between consumer and provider must focus on making the system as responsive as possible, providing the necessary supports and empowering individuals to move toward a desired goal.

Consumers are driven mostly by the issues associated with disability. Many people with disabilities who have a more active social conscience tend to work within advocacy groups and are motivated to change the system by their own experiences and observations. The most important element here is experience. Consumers live day-to-day with the problems resulting from disability, and from the systems set up to serve people with disabilities. Their greatest hope is to directly and effectively reduce those problems A good example is found in technology. The frustrations of living with marginally useful or broken equipment can be overwhelming. Wheelchairs, cooking aides, or communication boards that do not work or do not work well enough for the individual to function can drastically reduce quality of life. It is equally frustrating to know, or be counseled to use, technology that is neither available nor affordable.

If one were to reflect on the most successful individual venture in rehabilitation, it would be where the person with a disability takes charge of the situation and invests in whatever action is needed, and completes the process. Consumers are more likely to participate if they believe their involvement will have an impact on their own circumstances. Like most humans, consumers expect results, immediately and in the future. If none are forthcoming, then the system can expect to hear the voice of advocacy. During the past few years groups advocating for the reform of rehabilitation have become more strident, resulting in major shifts in the wording of the Rehabilitation Act Amendments of 1992, as one example.

Consumers want new knowledge that will make a difference in people's lives. They want reliable information that will not change or be reversed. They want advice about directions they can take to resolve their problems. These desires drive consumers to work toward change in their own lives, in improving service delivery systems, and in advocating with others of similar interests toward these goals. This power can be embraced by researchers and practitioners to further the ultimate goal, supporting independence and community integration.

Empowerment. The impact of the passage of the Americans with Disabilities Act is evident. This event has placed the rights of persons with disabilities on an equal ground, making the possibility of access to all the vicissitudes of life real. This, and other changes, are the culmination of the collective efforts of disability rights activists to stop discrimination against people with disabilities. It engenders a renewed confidence that individuals with disabilities have the power to influence change in keeping with the rehabilitation philosophy of preparing, or teaching people to get back in control of their situation. For much of history people with disabilities have felt denied this right. The collective efforts of activists speak to the personal, interpersonal, and political power that are key ingredients to empowerment. The rehabilitation community must accept, embrace, and value the perspectives of people with disabilities if the system is to change and remain a vital component.

The Practitioner Focus

Rehabilitation practitioners are motivated primarily by their desire to serve and to improve the status of humanity. The original agendas of the organizations within which they work tended to support this mission. The bureaucracy constrains practitioners by imposing a variety of conditions. Need for documentation, imposition of lines of authority, criteria for eligibility, conditions on expenditure of funds, and control of time tend to invade the altruistic motives of practitioners. The incorporation of research, and of consumer participation are based upon professional needs, frustrations with the quality of rehabilitation services they provide, the organizational structure within which they work, and the political environment which influences the resources available for rehabilitation.

Organizational structures. As the original agendas of organizations have changed, so have the attitudes and priorities of those who work in them. Legislation can often set the tone for any service delivery system and provide a set of particulars that must be followed in order to receive funds. The people who work in these settings develop a set of work parameters and attitudes that reflect the political nature of the working environment which, of course, has been conditioned by the legislation that funds the program. An example can be found in the Title VII provisions of the Rehabilitation Act of 1978. Independent Living (IL) services were defined as being for clients who were without vocational potential, a small subset of those for whom independent living services were intended. To target this small subset of individuals a series of requirements and procedures was designed, diminishing the intended concept of providing IL services along a vocational continuum. The current efforts to introduce these and other concepts into the reauthorization of the Rehabilitation Act seek to modify this misunderstanding, and to make independent living services available to a broader spectrum. The paternalistic approach developed throughout institutions and as reflected in the community is being slowly eroded. The newer approach, interdependence, focuses on the concept that all members of a community can contribute to its well-being.

The Researcher Focus

Researchers are motivated by a quest for knowledge, intellectual curiosity, and a desire to improve the status of humanity. Most of these incentives would not yield any benefit for humanity without funding for research. While some funding sources are less restrictive and more supportive of the researchers' interests than others, all carry constraints.

Funding sources may determine for the researcher everything from the topic to be investigated, to how the research should be conducted, to how the results may be disseminated. Most researchers rely on grants from federal agencies. In the field of rehabilitation, the main funding agencies are the Rehabilitation Services Administration and the National Institute on Disability and Rehabilitation Research, both within the Department of Education. Other funds are available from the Office of Special Education and Rehabilitative Services. A newer source for medical related topics is the National Center for Medical Rehabilitation at the National Institutes of Health. There are others. Most of the grants, cooperative agreements, and contracts issued from these sources are for research on designated topics. Few funding opportunities exist for field initiated research, which allows the investigator to set the topic; and, competition is extremely fierce. Given the topics are primarily set by the funding source, the question then becomes, "How can researchers, practitioners, and consumers influence the identification of these topics?" The issue is one of setting priorities.

Organizational structures. Researchers must not only deal with the priorities of funding sources but also with their host organizations. Most funding agencies hold periodic reviews of their priorities. These reviews may include internal analyses, public forums, the convening of authorities from the respective fields, and invitations for public comment. There is very little attempt, however, beyond notification in the Federal Register, to provide opportunity for consumer and practitioner input. Just as our society has an overall structure and its sub-populations have structures of their own, so do organizations. Some organizations in which researchers work are very open to input from the community and special interest groups; others are more closed or exemplify the proverbial ivory tower. Some are more nurturing and offer considerable support and encouragement for researchers to develop their skills and pursue their personal interests. Others tend to be more rigid, locked into old traditions, and oblivious to the issues "on the street." Researchers who are seeking ways to put into action the tenets of consumer involvement and practice oriented applications, should seek organizations which will support these objectives.

Understanding and influencing the priorities of the host organization is, for researchers, a completely separate issue from that of the funding issue. Since most research is affiliated with academic institutions, the researcher must develop a separate set of skills to receive support from the host institution. Very little consumer and practitioner involvement in setting these priorities exists. If it is a university that requires research accomplishments for awarding tenure, then faculty are highly motivated to produce in areas that will carry the most weight for tenure and promotion. Topics tend to be more academic, focusing less on practical or applied aspects.

Political environment. Both internal and external political forces affect researchers. Internal forces include the relationship between the researcher and the work environment. The degree of involvement in community issues and pursuit of questions of personal interest can be severely limited by this relationship. In order to maintain employment or advance within the system, organizational priorities must come first. Other topics may be of considerable interest and value to the researcher, but must fall behind organizational topics for research.

External political forces can be seen in many forms. For example, the current administration in Washington sets the priority for a national agenda through the "America 2000" program. Previously, Bill Graves (1991), former Director of the National Institute on Disability and Rehabilitation Research, set national priorities for research when he presented his "Participatory Action Research" address. This kind of political influence is unavoidable and is a product of the system.

Conclusions

Building A Common Ground

The interdependence of consumers, researchers, and practitioners drives the rehabilitation process in a circular fashion. This triad of participants is seeking ways to make rehabilitation more meaningful, practical, acceptable, and functional. It is through this interdependent relationship that information presented by the researcher (regarding "best" practices, for example) should direct the practitioner forward through the process. The perspectives of the consumer groups should drive both the research focus and the delivery of services. If this common ground is to be reached there must be change in two areas. According to Condeluci (1991), "One is the perspective of the devalued groups (ed. note—in this context consumers are the devalued group). Hopefully this change is toward greater self-esteem. The other change is with the targets who have created the oppression in the first place."

The common ground among the three groups is found in their interrelationships. All have a common interest in the process and its outcomes; and in order for the system to function as intended, communication and understanding are essential. Communication and understanding are prerequisites to closing the gaps between the practitioner, the consumer, and the researcher. An example of this is seen in the changing methodology used to evaluate success or quality in the rehabilitation process. Both practitioners and consumers must communicate with researchers in terms of quantifiable and qualitative needs. Researchers can then make available more information related to the best practices in rehabilitation.

In the next chapter the inclusionary model will be explored more fully, focusing on the application of research to practice where consumers have a pivotal role in defining the outcomes of that process.

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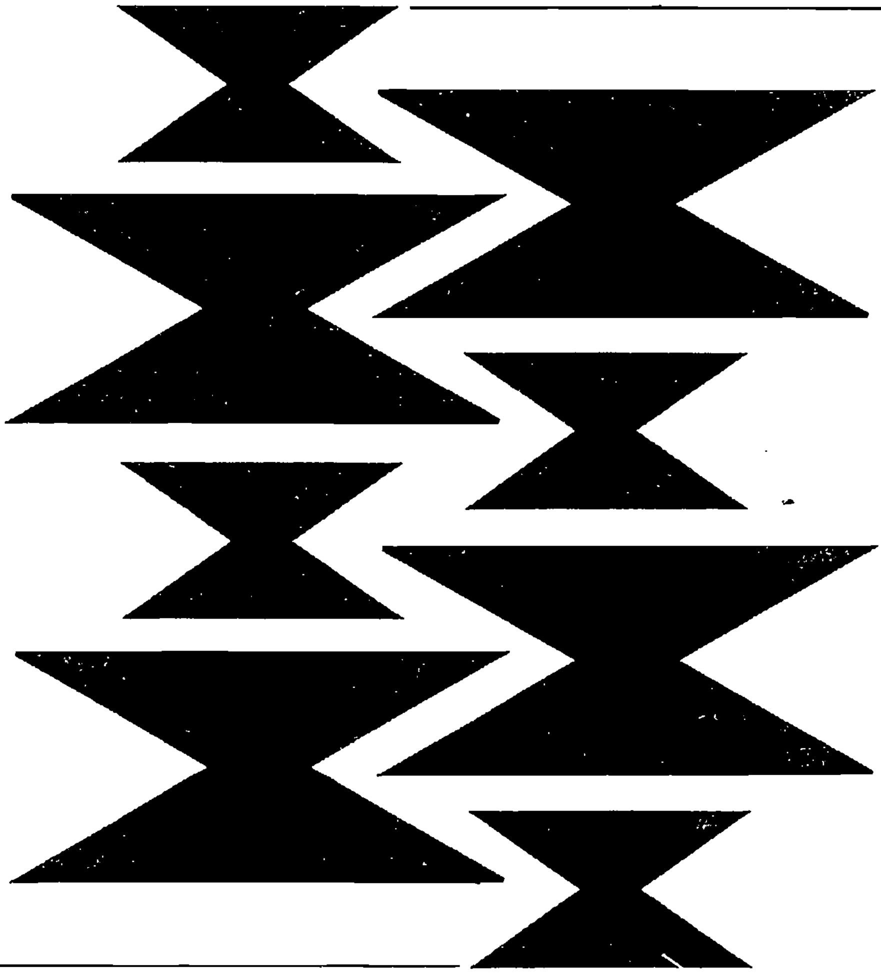
Strenghtening Applications from Research Through Involvement of Consumers and Practitioners



CHAPTER V

Strengthening Applications from Research Through Involvement of Consumers and Practitioners

Objectives

1. To explore the rationale for including consumers, practitioners, and researchers in all phases of research and its application in rehabilitation practice
2. To suggest how the perceptions and motives each brings to the research are different and supportive
3. To define the unique value of participants in rehabilitation research and application of research to the issues of rehabilitation and disability

Summary

This chapter examines the criticism that rehabilitation research does not meet the needs for solutions and applications which improve the rehabilitation of persons with disabilities. The text covers two major topics: a) what the rehabilitation field is doing to achieve a greater correspondence between research and its application to practice, and b) presents a working vision for increased inclusion of persons and organizations expected to benefit or use research in practice. This vision is presented as a base for the methodology presented in the next chapter. The premise of this chapter is that a viable alternative to the way research and development are presently conducted is one in which there is considerable involvement of those who are expected to be affected by the research; that is, consumers need to become "insiders" in the research process. A bibliography of references on participatory approaches to research and program development is included at the end of the chapter.

Discussion

The Problems in Connecting Rehabilitation Research to Practice

The difficulties in connecting rehabilitation research and development to practice are ones of scale, efficiency, and dispersion: difficulties arise in that there are substantial and complex problems which are a consequence of disability both for individuals and for the broader society. Difficulties occur because resources available to solve disability problems often seem to be unfocused, are not applied in any systematic fashion to the priority disability issues, and have not, to date, achieved the solutions which many expect from research.

Finally, the connections are difficult because of dispersion of the process across different sectors of concern. Priority setting among competing research and development needs are established in one sector. Problem formulation and translation of a priority into a research or development activity takes place in another. Research and development are conducted in yet another sector, most often by individuals unlikely to have been involved in either priority setting or problem formulation. And applications or adaptations from research and development occur in yet other sectors by people uninvolved in any of the previous stages.

While responsibility and blame may be leveled at any sector, the depth of need remains for valuable research and a more direct link from research and application to rehabilitation practice. There is a need to closely examine our expectations from research, and how research can provide immediate and long term solutions to problems which result from disability. Menz (1992, March) provided such an examination of its potential and applications in his discussion of the challenge this creates for rehabilitation scientists:

> Social attitudes, translated into agency policy, guides and shapes the research .... It influences and also creates various options to help forge a more productive link between science and application. [Policy can also] ... challenge the community of scientists to consider both the urgency of the problems that need solutions and their peculiar capacities to more readily assist in resolving those problems. For some of our greatest rehabilitation problems, the rate of progress in science cannot be dramatically increased. For example, the comparability and sustained benefits achieved by people moved from protected employment to supported employment cannot be answered through some experiment with carefully collected random samples, because present time is not sufficient to allow the assessment of those benefits; the program is too new. For other of our great problems, science cannot arrive at the needed, precise answers demanded by individuals directly affected by a disability. For instance, how aging, pre-existing conditions, and traumatic injury combine to affect the onset and course of dysfunction is now only beginning to be understood as more individuals have survived the acute stages and have progressed through rehabilitation.
>
> Yet, for other problems, the challenge will not be to unearth reliable, new knowledge, but to reconsider and focus the expertise and technology of research to understanding and explicating what does and does not work. We may need to more often choose not to chase the "elusive hypothesis" ... but instead choose to work with real people in real settings to verify what is reliably achieved with certain individuals and how those effects are achieved. *Probably among the greatest challenges, to those who think of themselves as scientists, will be to responsibly reconcile our professional needs to look into the unknown and pursue questions of interest to our own intellectual growth and, perhaps, a responsibility to join such curiosity to solving some of the broader social issues to which our skills may add the new critical value.* (p. 6)

There are examples in the applied research and development literature of how consumers-customers-end-users are being involved in research. There are examples from the business sector. Whyte's (1990) classic work on participatory action research, the examples of "excellence" cited by Peters (1989), and others of strong companies that are in touch with customer needs). There are also examples from rehabilitation experience. For example, since 1975 the Institute on Rehabilitation Issues (IRI) has offered specific guidance on how to increasingly involve the customer and to promote their empowerment. In 1975 (Rice & Orsburn), the IRI addressed this in terms of the relationship between the counselor and client. In 1987 (Corthell & Griswold), partnerships among service providers and consumers were explored in the context of vocational assessment. In 1988 (Corthell & Von Boskirk), the concept of partnerships and empowerment, as they may apply throughout any rehabilitation process, were promoted. Were one to examine the techniques and processes suggested in those examples, one would find similar elements that could be readily translated for use in the present research and application situation (e.g., openness, communications, respect).

The independent living movement demands that authority and final decision-making about what is needed for a consumer is the role of a client, not the professional's responsibility. Regulations for planning independent living centers require high levels of involvement and direction from people with disabilities. Further, technology has been developed by research and training centers for carrying out regional planning of programs which have maximum customer-consumer involvement, especially as participants in needs assessment planning of services.

In 1991 (Menz), the Region V Study Group suggested a model for conducting needs assessment as required of state agencies in preparation for the state vocational rehabilitation plan. The central concept in that model is the requirement for involvement and inclusion of "relevant stakeholders" in all phases of the assessment and planning.

> Stakeholders are people and organizations likely to be affected by or affect any potential change. They include proponents and opponents to change. They have vested interests in what the agency does or can do and are found both inside and outside the agency. Stakeholders can be a vital resource at all points in the assessment and planning: for ideas about how and where to get data, in instrument development, in collecting data, and in interpreting and developing implementable change. (p. 74)

Other important principles were proposed by the Study Group to achieve change through needs assessment. These concepts are applicable to our interest here in making effective use of consumer involvement in research and development, and for achieving change and innovation as an outcome of research. Those principles are as follows:

1. Intentional expectation during all phases that research findings will be used in decision-making,
2. Planning for utilization beginning at the onset of the study,
3. Recognition that neither the research nor its recommendations are conducted or used in isolation from other activities, priorities, or sources of input guidance available to those who make use of the research,
4. Inclusion of important change agents throughout the research is necessary,
5. Careful application of quality control throughout all the needs assessment and planning creates credibility for the research, and
6. Recognition of the importance of accommodation in linkages between the research, decision-making, and change.

In 1991, the National Association of Rehabilitation Research and Training Centers convened a study group to catalogue examples of consumer involvement in rehabilitation research. The initial findings of that study were reported back to that Association in the spring of 1992 (Seekins, 1992). As research literature is rarely codified according to research methodology, it was not surprising that Seekins and his colleagues found few citations of research involving consumers. Yet, his group's efforts did yield a sizeable number of examples from their survey of the network of research and training centers.

The Association's report suggested a variety of roles in which these centers involved consumers in the research, but noted that rarely were consumers systematically involved in each and every phase of the research. A reinterpretation of the variety of roles Seekins found for consumers in research is presented in Table 1. Several of the research and training centers identified in the report have become quite public in how they are attempting to promote and involve consumers and other

Table 1. Consumer as Roles Identified by Research and Training Centers

Consumer as Information Resource

Respondent to needs assessments and surveys.

Participant in focus groups.

Subject in research study (i.e., the traditional object, data source)

Specialized information source on personal impact, to sensitize, on priority issues, on quality of the research, as source of information on other relevant research.

Consumer as Functional Resource

Member of research project advisory boards.

Member of relevant networks which include

- Organizational and/or consumer networks;
- Participation in community, organizational, consumer development;
- Provide links to advocacy, program, policy sectors.

Advocate for research including

- Promotion of project aims;
- Teaching and educating other relevant "participants;"
- Accessing subjects or data sources needed in research; and
- Developing involvement among members of a constituency group.

Consumer in Research Operations

Collaborator in the research project such as

- Co-authors of research projects;
- Co-designers of methodologies;
- Conductor, experimenter, interviewer;
- Research assistants and associates;
- Co-authors of research-based publications; and
- Role cross-overs including participants serving as researchers (consumers, family members, others affected by disabilities, practitioners as researchers).

Consumer in Partnerships for Application and Research Utilization

Products and applications, including

- Reviewing and translation of research documents;
- Interpretation and use of research findings; and
- Identification of applications of research for policy and program development.

Dissemination and marketing, including serving as

- Co-presenters;
- Co-authors;
- Direct marketer or promoter;
- Creator of awareness/need for change within relevant markets; and
- Providers of technical assistance in adopting innovation.

Advocacy by

- Preparing community, organizations, consumers, or other institutions for utilization and adoption development;
- Collaborating in developing networks within which the advancement or solution can get consideration; and
- Linking and working through other relevant advocates, programs, and policy sectors to establish conditions for adoption of research solutions.

constituencies in the whole range of research. Notably, the Vocational Center at Wisconsin (Menz, 1993), the Beach Center on Families at Kansas (Turnbull & Turnbull, 1991, 1992), the Supported Employment Center at Virginia Commonwealth (Wehman, 1992), and the Vocational Center at Arkansas (Schriner, 1990) have each published models on consumer involvement participation.

Making Connections: The Case for Involving the Broader Range of Players

As the Region V Study Group (Menz, 1991) and many of the research and training centers are finding, people and organizations who are affected by or benefit from research and development can be involved in very significant ways. The new participants are alternately identified as stakeholders, constituents, beneficiaries, end-users, and consumers, among other terms. By whatever name, they can be the "players" and "insiders" in the research and development process. Ideally, they should be involved from inception and prioritization of needs for an applied research problem, throughout the technical phases of research and through the translation of research into practices that are appropriate for individuals.

The players are not members of some committee brought in to make sure the "research" and the "practice" are socially appropriate or popularly supportable. The players are people who will promote things that work, including practices that may not appeal to "popular" perceptions of what is possible. The players bring something unique to the search for workable solutions to the problems of disability. The players in this text are the consumers, the practitioners, and the researchers.

Consumer. "Consumer" in this document refers to people who will be most directly affected by the research, and by a practice that might derive from the research. Consumers include the people directly affected by disability and people indirectly affected (significant family members, friends, coworkers, employer of persons with disabilities) who are significantly involved in improving the quality of life of such individuals outside the "systems of care."

As the reader goes further into this document, it will be found that the authors are not proposing a patronizing view of the "consumer." Rather, the authors recognize that consumers bring sensitivity, history, experience, and understanding to the disability issue. When the text speaks of consumer involvement, it means involvement consistent with the consumers' ability to share, participate, and lead the research-development effort.

Practitioner. "Practitioner" in this document covers a broad category of professionals and paraprofessionals involved in affecting, causing, controlling, or delivering the "systems" of care and rehabilitation. They are inherently involved in one way or another in applications from research and innovation. They include, for example, the professional rehabilitation counselor, the peer counselor, the rehabilitation administrator, the public policy advocate, the social service or welfare bureaucrat, the case manager, the job coach, the trainer, the teacher of consumers, the teacher of other practitioners; all of whom may be proponents or opponents of change which the research determines is needed.

In real terms, these are the people who make innovation go or who stand in front of "system-society-institution-wide" adoption of innovation. However, they too possess knowledge, skills, and experiences about what "have been" effective and ineffective practices for people with disabilities. When speaking of practitioner involvement, the authors are not speaking narrowly about one group of people in a service delivery unit or program. Rather, the text is speaking of the person(s) who can advocate, implement or access resources which will reduce the impact of disability.

Researcher. "Researcher" in this document refers to the people with "inquiring minds" and meaningful training and experience in the philosophy, theory, and technology of the research and development processes. They are inherently involved in finding or creating "realities" that can be replicated. They are skilled, informed, and competent. Above all, they are concerned about acquiring new knowledge, eliminating myths, and achieving functionally valid improvements in rehabilitation. The authors do not distinguish the quantitatively from the qualitatively oriented researcher, the experimentalist from the evaluative researcher, or between competent researchers according to some other seemingly meaningful dichotomy.

While researchers often times have many of the answers to questions asked by both practitioners and consumers, they are apt to be more cautious, tentative, and conditional in applying answers to real conditions. Steeped in the traditions of scientific inquiry and a high regard for the processes of systematic inquiry, researchers are more often of greatest value when they impose order and quality control onto the search for innovations and solutions. When researcher involvement is discussed, the text does not make any assumptions about their position on a hierarchy. They are neither mechanic nor expert in this vision; rather, the authors speak of the unique role and shared responsibilities they bring to a common search for better rehabilitation solutions.

Making the Connections: Their Common Goal

Figure 1 provides a sense of how these three players differ in their motives as they seek help or begin to take part in rehabilitation research and development. They each bring different hierarchies of need, or, if you will, have different priorities. Among the three players, the figure suggests the intensity of needs which the consumer will have for concrete solutions, impacts on an individual's disability, or increased access which the research may yield. In many regards, the practitioner and consumer hold similarly intense feelings for concrete solutions, but differ in their priorities in subtle ways. The need of the practitioner may be for concrete solutions which have value for consumers with many different kinds of rehabilitation problems.

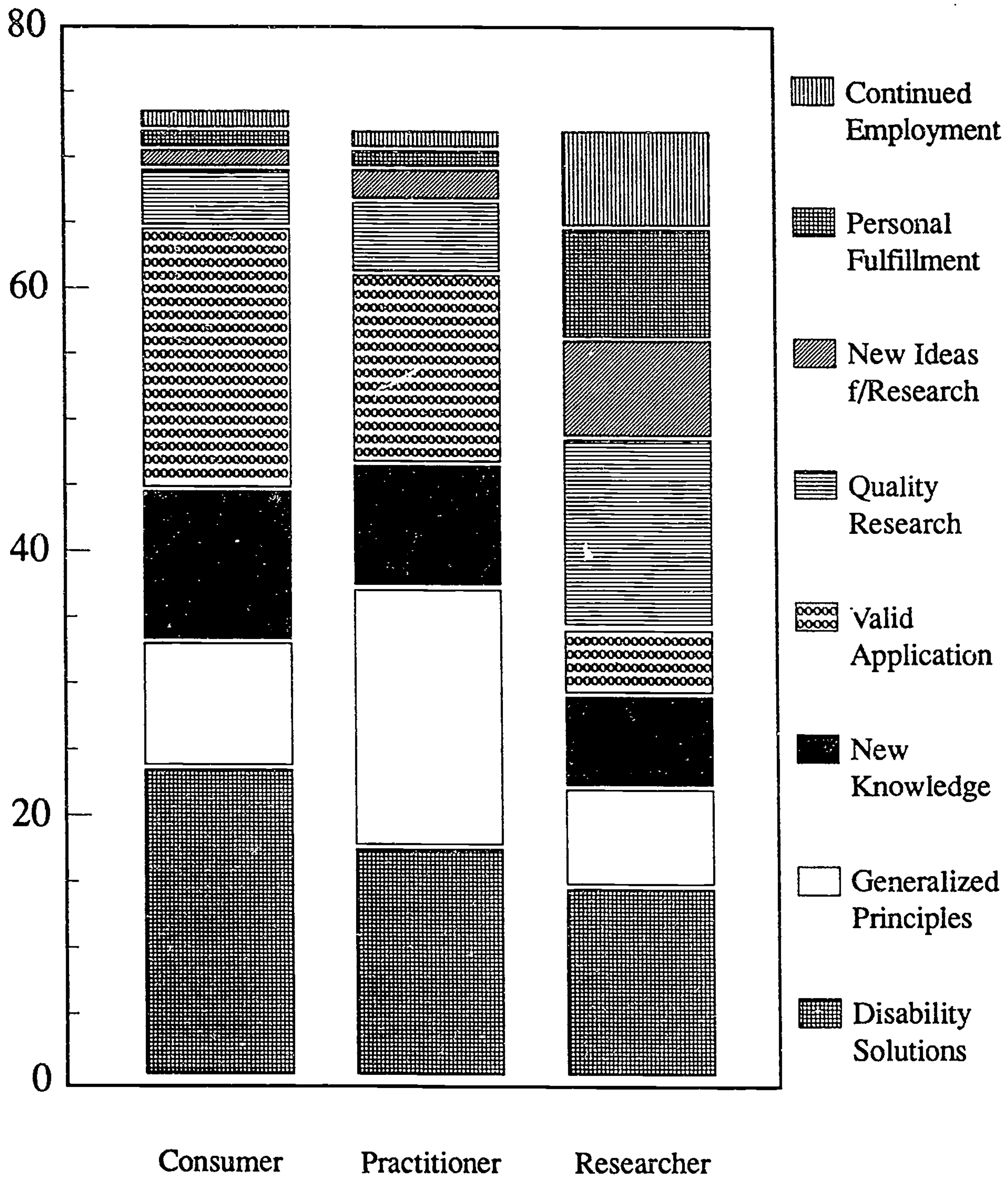
The researcher profile in the figure reflects those things which attracted and have kept them working in rehabilitation research or development. While the need to arrive at solutions for individuals is an important priority, their knowledge and experience affects what they expect they can contribute to such needs. Though the three have these differences between them (as suggested in the profiles), there are grounds upon which the three can truly complement each other. There are both common and uncommon grounds which may make their combined contributions substantially greater than those currently achieved by each separately.

The common grounds which can unify the three are their "desires for a better reality:" Reality of need, reality of disability, reality of possibilities, reality of capacities, reality of concern, reality of the search. The valuable and uncommon grounds they bring are their "unique perspectives": Unique perspectives about problems, priorities, processes, utility; about how the work of research gets done; about roles in rehabilitation, research, and development; and about what are quality responses and answers to problems of disability.

All three are interested and demanding of improvements and solutions. Research can offer important parts of the solutions. These insiders, in consort, can learn how to make better use of research: Together they can learn how to synthesize research to arrive at understanding and limited solutions to rehabilitation problems, learn how to use research to clarify needs, and learn how to classify the options brought about by new knowledge from research. They bring different needs and perspectives, but they share a common goal. They can achieve real solutions if they are willing to involve themselves by bringing their unique perceptions and energies to the search for solutions to rehabilitation problems.

Figure 1

Needs and Expectations from Being Involved in Rehabilitation Research



Conclusions

The criticism that rehabilitation research has not yielded adequate solutions to the rehabilitation issues was discussed in this chapter, along with examples of how the criticism is being answered in rehabilitation research. In general, the field has suggested that significant gains could be made if more people directly and indirectly affected by disability were included in the search for solutions to problems individuals and society face because of disability. The chapter examines how different "players" or "stakeholders" approach problems in disability based on their unique needs and expectations of research or practice. These unique needs, the chapter concludes, can be capitalized upon if considered for the potential contributions of alternate perspectives can contribute to the design and conduct of research and practice. A methodology for maximum inclusion is proposed in the next chapter based on this vision. The methodology details how the unique contributions of the various players can be practically built into the traditional research and development model. A subsequent chapter provides a case example of how that methodology works with a real problem in rehabilitation.

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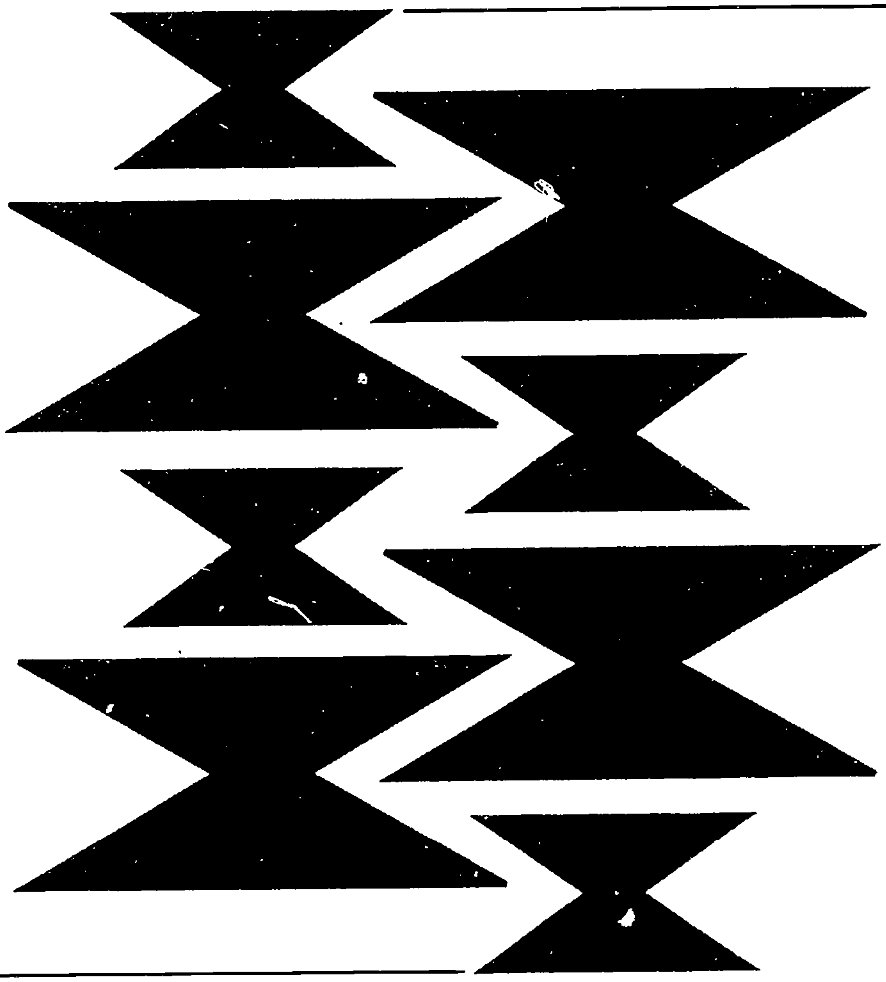
Making the Connection: A Methodoloty for Involvement in Research and Practice Explained



CHAPTER VI

Making the Connection: A Methodology for Involvement in Research and Practice Explained

Objectives

1. To explain the research-development process
2. To demonstrate how involvement of each player can take place
3. To suggest necessary conditions to make the methodology work
4. To suggest how collaboration can yield concrete solutions to rehabilitation problems

Summary

The previous chapter discussed how rehabilitation is attempting to increase the yield from research by increasing the involvement of consumers and other key beneficiaries in the research process. That chapter suggested how consumers, practitioners, and researchers are all key players in the search for adequate solutions to rehabilitation issues. As "players," they approach problems in disability based on their particular needs, a strength untapped in current research and development. Their unique needs can be capitalized upon if viewed for their potential enhancement to the design and conduct of research and practice. The connection between them is their common goal, their "desire for a better reality." They each bring "unique perspectives" about problems, priorities, processes, and utility; about how the work of research gets done; about roles in rehabilitation, research, and development; and about what constitutes quality answers to the problems of disability.

A methodology for maximum inclusion is proposed in this chapter which is based upon the traditional research process. The chapter details how the unique contributions of the various players can be practically built into the traditional research and development methodology. The text provides a rationale and methodology for involving consumers, practitioners, and researchers in a continuum of research practice endeavor. Further, the chapter explains how the perspective each has to offer can be combined to yield more timely solutions to critical rehabilitation issues. A subsequent chapter provides a case example of how that methodology works with a real problem in rehabilitation.

Discussion

Making It Work

The process described below will not occur automatically. Before detailing how the methodology would be organized and structured, let us first talk a little about what is necessary to make it work. First, it requires rethinking how and by whom research is conducted and how each player can be meaningfully involved. Second, making it work requires an understanding of what is required among those participants who elect to become involved, and requires careful attention to what each brings to the research and change processes. And third, making it work requires that each player retain his/her vision and work respectfully with those who have different motives but share that vision.

Unique contributions of the participants. No two consumers, practitioners, or researchers are alike. The three participants described here have in common a maturity, an informedness, a concern, and a mutual respect. It is upon such traits that they can build a research and change process (like that suggested above) which can have high yield because **the three are each "experts" within a role.** They have unique knowledge, experiences, skills, values, and needs to achieve rehabilitation solutions. Likewise, they have shared concerns and knowledge which makes it possible for them to work together. This is what each brings to rehabilitation problem-solving that can make the difference; not whether one person can or cannot possess capacities of all three roles. The separate and respective values of each role are what it can provide, add, or combine with to produce a more refined understanding of the problems and the solutions[1].

Functions fulfilled by participants. During each stage of the research, the three players might fulfill different functions. Each function listed on the following table is one commonly needed to conceive, carry out, and make use of research findings. While the listing is not exhaustive, it is quite suggestive of different roles the researcher, the consumer, and the practitioner might assume as they move between the several stages. Potential problems may be partially abated when each player clearly recognizes such roles and the functions they serve during the several stages.

Requirements of the players. The methodology described below promotes ways by which those who are to be affected by the research can be meaningfully involved in rehabilitation research and program development. They become "insiders" in the research process in much the same fashion as the researchers and those most informed about the value of the research (e.g., funding agencies, other academics). The challenge they face is envisioning ways in which the contributions of each can be drawn out and combined to enrich the quality of the research and to validly change practice. As involvement is extended to include all three players, however, the forms of involvement cannot be passive or merely token gestures to "equitable participation." Besides being insensitive and insulting, token involvement adds nothing of value, yet represents a costly nuisance in an already difficult venture.

A Methodology for Inclusion

Research can be adult learning at its best. Regardless of the research problem or methodological predilection[2], the research process has traditionally been described as having five interrelated, functional stages. To these five, a sixth stage is added to insure the linkage between research and it application to practice. The stages are interrelated and do not always occur in quite the linear fashion described below. In the discussion, the authors attempt to demonstrate two things: First, what is achieved within each stage, and second, how each stage helps guard against cumulative errors in judgment, procedure, inference, and conclusion. It is important that each person involved in the research process understand these stages in that they guide how the different roles discussed above are seen and best used.

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[1] Appendix C includes a chart the reader may wish to use to evaluate and document the unique attributes the three players would bring to research and practice problems. One might use this to stimulate discussion and planning of the particular composition of the "group" in relation to a potential research or development effort.

[2] The authors do not make technical distinctions between different kinds of research used to resolve rehabilitation issues. Rehabilitation research is highly complex. The purposes of research range from finding direct answers to specific questions, to research to develop a new technique, to research to eliminate errors in practice, to research to achieve new knowledge, to research which systematically contributes to theory. The issues of disability cross over the disciplines of health, employment, economics, and human services. Various methods are valuable for advancing quality solutions in rehabilitation. The authors therefore consider very broadly how multiple perspectives and participation might be effectively brought into the research processes and how more meaningful solutions may be achieved if such an approach is seriously pursued.

Table 1. Functions for Consumers, Practitioners, and Researchers in Research and Development

Facilitation. Promotes the interplay and exploration of perceptions in order to achieve a consensus on purpose, direction or strategy.

Leadership. The result of having achieved consensus among the participants in the research process.

Management. Responsibility, authority, and efficient coordination of the research and or development activities.

Support. Clerical, record keeping, data collection, encoding, transcribing, other activities needed to complete the research.

Expertise. Specialized knowledge or capacities to access and or acquire needed information or to resolve problems resulting from research or application.

Mechanical. Specialized capacities to achieve or carry out a specific element or procedure in the research or applications plan.

Production. Worker-bee, grunt, research assistant who carries out a finite activity in the research or applications plan.

Information. Data or information resource that can only be obtained from the individual as subject in research, member of focus group, or other function.

Analysis. Analytic and synthesis functions to achieve a valid condensation of critical information or data.

Interpretation. Application of prior knowledge and/or the accommodation of reality within the matrix of information produced through the research.

Application. Seeking meaning beyond the specific research, deriving ways which the research provides improvements in the lives of people or constituents affected by the disability.

Monitoring. Quality control methods or techniques applied to insure the highest degree of validity and replicability, apparent benefits, findings, and/or impacts.

Historian. Contrasts current information with previously existing information. A part of the quality control effort, but gives special emphasis to whether research repeats valid techniques or a known faulty practice.

Design. Conceiving methods to sensitively address the research issues or to insure that alternatives to which the research may identify are likely to have applications beyond the original research conditions.

Evaluation. Critical and sensitive appraisal of what the research produces. This is the conscience-less critique to discover where the research has and has not yielded anything of value.

Advocacy. Intentional promotion of the research and/or the options and changes which it has yielded. Intent is to create and support those networks and conditions which are likely to insure widest implementation of an application or research finding or innovation.

Arbitration. Provide an objective means for balancing competing interests in a research plan or in the support of options that may be validly pursued as a result of the research. The function is to insure fidelity to the results from the research or demonstration.

Formulation of the problem. This stage will often begin well before anyone realizes that research or development will be undertaken. Most obvious is the point in time when "research priorities" are being established by a funding agency (e.g., the National Institute on Disability and Rehabilitation Research). In this stage, both a narrowing and broadening of ones initial understanding of a "problem or experience" takes place.

It is somewhat like taking a personal example (e.g., "my brother has AIDS"), or a social concern (e.g., "too many people like me can't get jobs"), or a specific program concern (e.g., "our counselors' performances seem inconsistent"), and considering it as fully as possible. Collectively, the players know more about what is involved in the problem because of their different perspectives and different sources of information (e.g., experience, training). Reasonable priorities are set as the many perspectives are interrelated and a working consensus is reached about what the "important problem is," and how much of the problem might be solved with the resources available.

This is the stage during which the players separate the nontrivial issues from the truly trivial ones. This is also the stage in which they start to conceive potential solutions to the nontrivial problems, and which of those solutions may be of more or less value as alternatives. It is at this stage that one should decide whether the identified problem is a problem worth pursuing through research, whether there is sufficient knowledge to "invent" a solution, and whether resources are available to do justice to the issue. It is also at this stage that each player should begin to anticipate how solutions to the identified problem might lead them to change the way things are done, to anticipate some new intervention, or to introduce some new preventive step. In effect, as the problem is clarified, each player begins to anticipate and begins to plan applications from the research that will follow, nascent though such plans might be at this stage.

Each of the players has something different to offer at this stage. Each has a unique perspective and scope of contributions. The consumer has depth of knowledge about the course of their response and the consequences for them coming from disability. The practitioner has experience in use of current practice and knowledge of the limits of present technology in attempting to trace or ameliorate those consequences. The researcher may have a broader knowledge of the accumulated research relevant to the problem of interest. While the researcher has the analytic skills to separate specific issues and detail the research problem, it will be the depth of personal and practical understanding of the problem, which the consumer and practitioner introduce, which will determine whether that technical expertise is more or less worthwhile. Consider the following as an example of how the three players interrelate, and how their understanding of a problem might take place:

The initial statement of a personal issue. The process begins with a simple statement of concern. "My brother and many of his friends have AIDS. He is scared and his family and friends want help."

The research problem begins to evolve. The informed perspectives of consumer and practitioner and researcher are explored, integrated, cleaned up, and united to form a rational picture of what it is that needs solving, and what a solution might look like.

Consumers are drawn upon to sensitize others to the real experiences of learning of the diagnosis, personalizing and rationalizing it, denying and projecting anger and fear, dealing with acquaintances, and discovering the economic as well as health consequences.

Practitioners sensitize each to the economic and rehabilitation limitations involved with current systems and the seeming pattern of changes brought about among individuals known to have AIDS.

The researcher shares recent scientific information, facilitates a mapping of the player's perspectives, and helps them understand what other medical and social research may yield during the period of time they all may be concerned with this issue as a research problem.

The three players arrive at a consensus about the important issues, a priority among those issues, and a general sense of the scope of a problem that can be reasonably addressed through research.

A statement of the research problem is achieved. What are the social, economic, and rehabilitation consequences of AIDS for males 21-40 in Peotone, Illinois? To what extent do age at onset, education, sexual preference, availability of supports, medical access, and prevailing community values increase the adverse consequences of the diagnosis? To what extent are attitudes and responsiveness of persons within the individuals circle of acquaintances (family, friends, co-workers, churches, employer) instrumental to an individual dealing with the disease?

Identification of tentative research applications. Public information on the etiology of AIDS, risk in contagion, limitations to social and vocational functioning are jointly listed. Potential intervention strategies are proposed for co-workers and families, for controlling the day-to-day changes in capacity. Potential rehabilitation strategies for job restructuring, personal estate planning, and grief counseling are sought. Organizations and other resources which need to be prepared for access, given the potential solutions that this research may produce, are identified (e.g., churches, social agencies, area clinics). Additional "insiders" who may become involved in the research stages are identified and now include counselors with active AIDS caseloads and emergency care workers at area clinics.

This stage helped each participant better understand the context of "the real research problem" and its consequences. They are better able to recognize the interdependence of personal and professionally based resources and factors early in the problem's identification. Some of the possible factors or variables that might be controlled in the research study are identified. Other factors will acquire more meaning as the research continues, but all participants begin to consider what may be involved as the research concludes. They have begun, in their identification of resources that need to be available for individuals with AIDS, to anticipate applications of the potential research findings.

Having "gone through this stage" does not mean that players have a complete understanding of the research design, execution or interpretation of the research results. Problem clarification, particularly in rehabilitation, is almost serpentine, insinuating itself throughout the other research stages. Clarification of the "problem" continues as new knowledge is introduced from the research results, and as the informed players are able to invest more from their growing understanding of the problem throughout the research process.

One might suggest that an important outcome of the entire research methodology described here is that of achieving a clear and common understanding of the real problem. The outcomes of this stage, however, are the following:

1. Identification of a priority topic for study;
2. Identification of constraints, opportunities, causal factors, environmental constraints, and relevant practices-issues to consider;
3. Identification of potential utility and utilization plans; and
4. Creation of conditions that will help assure greatest yield from the research.

Planning the research. The term "plan" has an especially important meaning in rehabilitation research when application of the research in practice is intended. A research plan is a formally written set of guidelines and principles which control how the study of the problem is carried out. It is an agreement between players about the resources that must be acquired and how those resources will be used. The research plan puts restrictions on how broadly and narrowly the research inquiry will go, how the necessary research data will be acquired, and how data are dealt with once they have been obtained. While it is not a device to constrain the search for valid answers, it is intended to contain enthusiasm and reduce the influences of personal-perceptual biases about what is and is not real and what is and is not replicable. In effect, it establishes quality controls for these "inquiries."

One of the characteristics of a good research plan in rehabilitation (and probably in any other scientific area) is that of "sensitivity and flexibility." This means that the research plan, while keeping attention focused on the primary problem, builds in a capacity to grasp such data that will better align the research activities to the most pertinent aspects of the problem. Common examples of such safeguards are in pilot tests of survey questionnaires, pre-testing of a proposed intervention, and tryouts of computer programs with real people.

The purpose of these "trials" is to make sure that the activity provides the kind of data required in the research, not to make sure that it will provide the kind of evidence to support a particular point of view. There is probably nothing quite as frustrating in research as having to conclude that the results are questionable due to technical flaws (e.g., due to application of a particular technique, failure to ask what became the most obvious question). There is, also, probably no more justifiable criticism of the value of research when this occurs.

Monitoring against "sensitivity checks" in a research plan is desirable. These checks help keep the research focused on the "problem," rather than becoming distracted by inappropriate *a priori* assumptions about the experimental condition or by the seeming importance of a single element in that plan. Equally important, monitoring allows the plan to be empirically adjusted. Monitoring should cause one of three things to occur: Provide signals which clearly indicate (a) that the research is going smoothly and need not be interrupted, (b) that the research is not fruitful and limits any further expenditure of scarce resources, and (c) that the research is off-target and what might need to be done to refocus the effort.

There is tradition and considerable literature which the competent researcher will draw upon when preparing such a plan. However, the researcher need not take the lead for translating the research problem to a research plan. Planning is greatly improved when alternate perspectives are incorporated and the evolution of planning activities shared. From each participant's perspective there are abiding questions that should guide them, whether evaluating a specific element or the overall plan. As consumer, as practitioner, or as researcher, each participant has much to offer to the development of a solid plan. Some of the basic questions each player should keep in mind relate to input, evaluation of quality of the plan, and further participation in the research plan, as summarized in Table 2.

A number of the activities that take place during this stage are technical. These distinguish research from other less formal ways of getting information to support ones own perceptions of reality. The activities are all focused on preparing a working plan which best assures that the research will yield valid findings, with minimal errors due to poor planning or bias, and suggest potential applications. The research plan will achieve or include the following:

1. Define interventions or treatments that will be part of the research;
2. Formulate research questions to guide the research or hypotheses which will be tested during the course of the research;
3. Identify relevant independent and dependent variables that must be considered in the research;

Table 2. Basic Questions to Guide Player Participation in Development of a Research Plan

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Input to the Plan

What would I propose for any of those elements of the design?
Are there issues that I am aware of that should be considered or addressed in this plan?
Do I understand what is going to take place and why it is being done in the planned way?
What is my understanding and opinion about each element?
Does this plan make sense?

Evaluation of the Plan

Is what is in the research plan relevant to the problem?
Can this plan work?
Does this plan include enough checks for monitoring to insure success?
Is there a more efficient or effective way to go about this research?
Is this plan sensitive and respectful of the needs, rights, feelings, and capacities of the people involved?
How well do the proposed plans for application coincide with the research plan?
How might this plan be improved?

Commitment to Participate in the Plan

What sources or resources might I identify to effectively achieve the plan?
Which of the participants has the better resources (e.g., access to subjects) or capacities (e.g., knows how to talk with certain groups) to do what is required?
What part(s) should I, or others, play in carrying out the research?
What should I watch for as I monitor the project's progress?

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4. Identify sources for obtaining needed data and appropriate sampling techniques;
5. Identify needed instrumentation, technology, and interventions;
6. Specify quality control checks;
7. Describe how the utility, appropriateness, and interdependence of the research will be piloted and verified;
8. Outline the responsibilities and commitments of the players in the research process; and
9. Outline procedures to operationalize and efficiently manage the course of the research.

Conducting the research. This stage includes the time when the data needed for decision-making are actually acquired. The agreed upon plan is operational and the plan is modified according to monitoring results. Quite likely, understanding of the research problem again grows or is refined. This stage is one of two stages (analysis is the other) characterized by "objectivity" and "compliance to agreed upon rules." Quality control is its hallmark. This stage insures that the appropriate data are sought and accurately observed and reported. This stage begins with selection of samples, implementation of any interventions or treatments, and collection of needed data. It concludes when data are verified and codified for analysis.

Quite often, in traditional research methodologies, this stage is left to the researcher. Participation of consumers and practitioners in this stage, however, is quite advisable when the concern is to arrive at relevant applications from research. While there are a variety of ways in which consumers and practitioners might be meaningfully involved, two major forms of involvement seem desirable.

The first form of involvement is in monitoring how the research plan is carried out. Both consumers and practitioners should monitor how the plan for research unfolds and apply their perspectives to how any variances from the plan are accommodated. To a great extent, consumer and practitioner participation may be especially beneficial in that they are less likely to be invested in the details of the research process. As intended, they may be more "objective" and aware of "compliance with the rules" and are more apt to promote appropriate changes to the plan.

The second form is to become involved in carrying out selected parts of the research plan in conjunction with the researcher. While some activities require specialized training (e.g., in observing and recording behaviors, in interviewing, in administering a treatment, in coding data) many of the activities may be better carried out by "para-researchers." For instance, in studies of people with severe disabilities, a researcher may not have the level of sensitivity that can be found among persons who have a disability or who have worked with numerous people with disabilities. The researcher, in these cases, may not be the best "observer and recorder" of data or may not be best prepared by experience to document and describe the "therapeutic interventions" that take place. Access to people (both physically and as intimates to their thoughts) may be limited for the traditionally trained researcher. Their awareness of nuance (regardless of instrumentation) may not be sufficiently on target. In such cases consumers and practitioners should be trained to conduct the interviews as they may be better observer-interviewers.

When it time to analyze and interpret research the players may all then share important advantages as they all have been involved in collecting the data. They can bring a greater appreciation of the apparent limitations to the analysis of the data obtained in the research. The consumer-practitioner, as researcher, has the advantage of being able to filter specific observations back through prior experience or knowledge. These qualities of understanding are difficult to relate and almost impossible to transfer to others.

Both types of experience afford the "researcher" subtleties to work with in their evaluation of the research findings. These experiences provide understanding and afford reasons for caution as the players subsequently work with quantitative and qualitative summaries of findings. As an informed and trained participant in any of the research activities, this involvement can enhance and sensitize all to the possibilities and generalizability of the research for practice, as well as make them aware that the research has perhaps not answered all of their most personal concerns. Above all else, the research team must acquire the following from this stage:

1. Valid forms of data respective to the problem under study, and
2. Sensitivity to the meanings and generalizability of data for resolving the research problem.

Analysis and reporting. The purpose of this stage is to reduce the mass of discrete and/or interrelated bits of information (i.e., your research data) to a communicable whole consistent with the research problem and research issues. The objective is to achieve as clear and as concise a knowledge of the problem as is allowed by the methodology. Analysis and interpretation address foremost the purposes, hypotheses, or major questions of the research. The analysis should assist the players to separate "what is now known to be true" (i.e., what is probably true) from "what remains unknown or uncertain" given the research method.

Each player can be valuably involved at this stage. As in planning the research, there are some abiding questions which each of the players should ask about the fidelity, usefulness, and appropriateness of how the data are analyzed, presented, and interpretated. Questions like those in Table 3 should guide each participant's active involvement in this stage of the research.

Table 3. Player Involvement in Analysis and Interpretation of Research Findings

Analysis of Research Data

What are direct way to analyze these data?

What safety checks are or should be in these analyses (i.e., to prevent incautious conclusions)?

Do I understand how and why the data are being analyzed?

Does any of this make sense to me?

Can anyone else replicate the analysis?

If I were doing this, how would I do it more effectively?

Can more information be legitimately extracted from these data?

Were these analyses correctly conducted?

Presentation of Research Findings

What exactly does this presentation tell me?

Does any of this make sense?

Does this presentation fit with what I understood the research and research problem to be about?

Is this presentation convincing, relevant to the problem, and justified by the analysis?

Are there better (i.e., more effective, more convincing) ways to convey the findings?

Interpretation and Drawing Conclusions

Would I, (or others), come to the same conclusions?

Do I disagree (agree) with the interpretation because the results do not argue convincingly or because it disagrees (agrees) with my own preferences?

Does this interpretation confirm (disconfirm) my own expectations?

What do I know now that I didn't know before?

Have the findings changed, improved, or added anything to my understanding of the problem?

What do these findings suggest for application to problems or issues in rehabilitation?

Who else should know about these findings?

Are there alternatives, changes, or options that should be pursued based on these research?

There is an impressive technology available to researchers to conduct data analysis in a systematic and quality controlled manner. This technology parallels the literature on research design. Too often, a variety of statistical and graphic tools are inappropriately applied, however. Worse, sometimes is thatthis technology often takes on a life of its own and becomes a source of "impression" and "illusion", lending little to the communicability of the research: Uninterpretable tables of means or percents; statistical tests that are inappropriate to the research design; interesting and attractive graphics which do not relate to the issue or suggest meaning that is not supportable by the research; use and reporting of high-powered statistical analyses applied when a simple presentation would suffice.

When an experiment comparing alternate medications (e.g., for AIDS) has been conducted, the analysis and interpretation should tell the players which of the alternatives has the greater likelihood of success and whether important subgroups (e.g., early infected males) will or will not respond predictably to it. When needs for services (e.g., among blind, urban diabetics) have been assessed, the players should be able to readily identify what are the important and unimportant needs. When the players evaluate the relative cost-effectiveness of competing delivery modalities (e.g., supported and non-supported option), they should not only be able to understand what "cost" and "benefit" mean, but understand (if not agree) that these are appropriate indicators for each of the options. More importantly, each of the players should have a certain confidence that the reported cost-effectiveness indexes could be reproduced if someone else were to apply the same techniques to those options.

Complexity in presentation is not the equivalent of sophistication or elegance. Neither should one assume that simple presentations are the same as accurate renderings of the problems findings. A technology for analysis paralleling research design is available to guard against simplistic, inappropriate, and unwarranted conclusions, given the quality of data available to this decision-making phase of the research. The outcomes of this stage may be the following:

1. Each player should know what was found and clearly understand what the findings might mean to them for changing or enhancing practice;
2. Consensus among the players should be achieved as to what the research has yielded as solutions; and
3. Each player should begin to identify (a) expected changes and implementation needs, (b) likely alternate resources and strategies to achieve change, and (c) ways to disseminate findings.

Synthesis and dissemination. Synthesis goes beyond merely accurate exploitation of the data and accuracy with which interpretation of findings are presented. Synthesis deals with preparing the important messages which the research has achieved and putting those messages into usable formats. The dissemination part of this stage is involved in getting those messages out to the right audiences using the mechanism(s) which are most appropriate to the message and audience.

What takes place during synthesis and dissemination is really an evaluation of what the players now know about the "research problem" and what they might do about it. In this stage the players shift from asking questions to strategically planning how to best go about getting the research used. It is somewhat like deciding what they can now "invent" to achieve the desired end.

In many ways, this stage parallels the problem identification stage. As in the problem identification stage, the research process affords the three participants an opportunity to take advantage of each other's unique perspective. In the problem identification stage, their efforts were combined to achieve a working understanding of "reality-of-the-problem." In this stage, each participant now has the added advantage of being equally informed of each other's perspective and able to share in findings which they acquired through agreed upon methods and rules of application.

Individually, they can add to their respective combined interpretations. They can contribute to a further synthesis which grasps the subtlety afforded by the research, and identify options which have credibility and authenticity within their own perspectives and/or hierarchy of needs. Given their greater common experience and learning, they may define options, alternatives, and applications which meet the needs of one or more constituencies which may not have been possible independently and ones which have greater likelihood of acceptance by others. It would be in this stage, working in concert, that they define workable strategies for achieving the broadest adoption of the research applications they identify.

This stage is characterized by reflection, interpretation, and strategic planning: identification of implied or direct applications from the research; definition of conditional factors which can promote or deter adoption; planning steps to access appropriate networks and institutions; and actions which achieve the desired applications. The focus is least on the research and most on how to best communicate, disseminate, diffuse, and increase the likelihood that the proposed outcome(s) will be used, adopted, and technically integrated into the fabric of the intended recipient of the innovation.

In this stage, the players are actually revisiting the applications they began to plan for at the onset of the research (i.e., in problem formulation). The benefits the players might expect from research and their accumulated efforts by the end of this stage of the process would be:

1. Consensus on the specific knowledge gained through the research and its value for constituencies;
2. Consensus on identified applications of the research findings;
3. Consensus on strategies to achieve adoption or implementation of the identified applications; and
4. Clearer understanding of the research problem and related problems that may yet need to be researched.

Transfer of research-based applications. This sixth stage is rarely found in traditional research discussions, except for research with clear developmental or marketing emphases. This stage is directed at "getting the message through" for those who can make use of the research to "make changes." Because the researcher is very often considered "objective" and "non-involved," there is not the anticipation that adaptation or adoption of a scientifically originated application would involve them directly.

Consumers, practitioners, and researchers are uniquely equipped to contribute in a complementary manner to achieving adoption of the applications identified in the previous stage. Given that the three players have traveled this far together, it probably would take little to convince them to continue on to transfer of research findings into applications in practice. Three general functions are envisioned for their continuing involvement in knowledge transfer: advocating for the research derived innovation, preparing conditions for adoption of an innovation, and in technical assistance in installation of the innovation.

Advocacy for innovation. Consumers, practitioners, and researchers each have access to different networks. These networks can be used to create awareness, to achieve support, and to provide resources to promote a new application or innovation from the research. In networks where the researcher may be less credible as an advocate for an application, a consumer or practitioner may be more credible. Where a consumer may create adversarial responses to a demanded change, the practitioner may have access to the systems and individuals who will give the potential change a positive hearing.

Preparation for implementing innovations. No innovation is put into place without having set in place conditions for its adoption. Whether it is "raw enthusiasm" or replacement of a standing practice, conditions must be established to accept and incorporate change. What these "conditions" are and how they will have to be changed need to be understood. Further, strategies need to be put into place which make it possible to adopt the innovation. Some conditions needing change are financial, while others are ones of tradition, attitude, and culture.

For example, it is not unusual for a "model practice" to fail abysmally when it is tried in a different setting than the laboratory in which it was developed. Too often, this occurs because the conditions necessary for its adoption are not adequately considered. Likewise, it is often the case that failure of an innovation really means that the new practice was "fit into existing ways of doing things," rather than replacing the older practice to the degree necessary. In both examples, transfer was unsuccessful not because the innovation does not work outside the laboratory or original setting, but rather because people and their institutions were not adequately prepared to incorporate the changes and the crucial elements of the innovation.

Technical assistance during adoption. There are at least four phases through which innovations must successfully pass before they are successfully incorporated. The unique perspectives that each of the players can bring to this sixth stage offer each participant an opportunity to help in bringing about successful adoption of the research-based innovation.

The first phase is when there is high enthusiasm for (or against) the innovation, when expectations for the innovation are more (or less) than is warranted for the new idea. The second phase occurs as people and organizations try to accommodate an innovation into present operations in order to minimize unnecessary disruptions and to convince those more resistant to change to accept the innovation. The third phase occurs as experience reveals problems or when flaws in the innovation and its adaptation are discovered. It is during this phase that the safety of older ways seems most appealing. The fourth stage occurs when leadership for the innovation, or an internal capacity to easily solve the problems, is not available, often during implementation and stabilization of the innovation.

Technical assistance can help the individuals or organization to pass successfully through all of these four phases. Phases two through four require different knowledge of the innovation and the research. Each of the phases offers important teaching and technical assistance opportunities for drawing upon enriched consumer, practitioner, and research perspectives. Which player perspective is most valuable in aiding a potential adopter of an innovation will depend on whether one or more of the players have acquired the appropriate knowledge and skills from the research and development experience yielding this innovation. Any one or more of the players may bring the believability, expertise, and sensitivity an organization needs to successfully pass through any of these phases.

A Word of Caution

The solutions which this inclusionary methodology can produce may prove to be of greater value than those we presently adapt from research. Greater rigor, credibility, and replicability may also be cumulative values fostered by the combined inclusion of consumers, practitioners, and researchers. However, inclusion and participation alone will not guarantee better research or more meaningful solutions. Without conscious attention to scientific principles, this approach can introduce new problems.

If validity and relevance are sacrificed for inclusion and consensus, both the research and the changes in practices that are devised from research will be no better than popular folklore. When balance is not achieved among the interests and where compromise overrides methodological standards, the new alternatives subsequently proposed as the products of research may be as trivial, isolated, and unreliable as some of those with humanistic appeal presently promoted in rehabilitation.

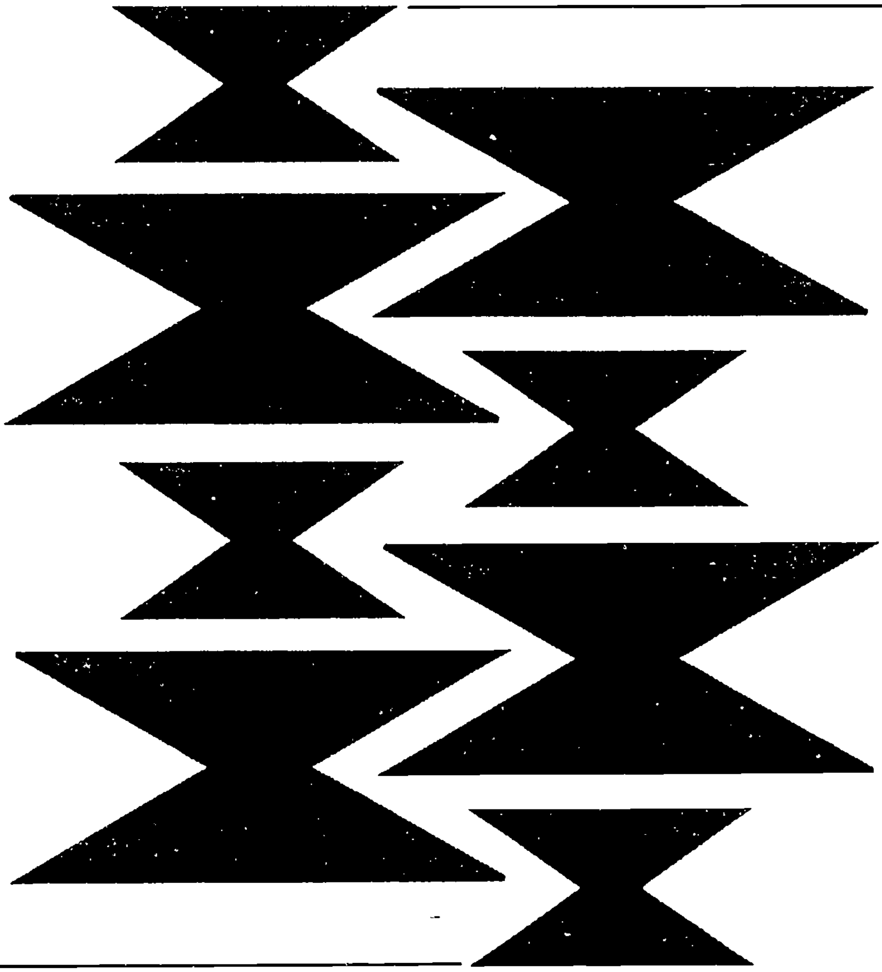
Throughout the use of this methodology, the participants must remain aware of these potential problems and remain quite clear about the functions they are each fulfilling in the research-change process. If not, their intentions to create better solutions to problems of disability will not be achieved.

Conclusions

A methodology was proposed to make the connection among the key players and to draw upon their particular strengths. The methodology builds upon the strengths of the traditional research processes, which insures validity in answers and solutions. To these, the methodology adds the combined contributions which each player can bring to the research and development effort. The methodology details how the unique perspectives of each player are brought to the endeavor at each of six stages in the research-to-application process. In combination, the discussion provides the reader an understanding of how the methodology can insure that valid solutions arrived at through research will be applied to the real problems in rehabilitation and create alternatives to the way rehabilitation is presently practiced.

The discussion of conditions necessary to this methodology reminds the reader that the same conditions are needed to achieve any important change: respect and valuing of unique needs and perspectives among those involved in change; declaration of functional contributions each needs to make at different times; and a common commitment to achieving change necessitated by their common goal. The chapter concludes with a word of caution lest our enthusiasm in applying this inclusionary methodology loose sight of the need for rigor and adherence to established research and development practices. The next chapter provides an example of how the methodology is applied to a real problem in rehabilitation.

Achieving Better Solutions: A Human Resource Development Example



CHAPTER VII

Achieving Better Solutions: A Human Resource Development Example

Objectives

1. To demonstrate how each player's unique contributions can be included in the search for solutions
2. To demonstrate how greater involvement can bring about directly useful alternatives to an important problem in rehabilitation practice

Summary

The example presented in this chapter was constructed around the six stages detailed in the previous chapter. It addresses the general problem of "how to devise an equitable performance evaluation process which will improve and sustain quality rehabilitation counselor performance." In the previous chapter the unique functions each player can bring to research-development as "players" were discussed in general terms. In this chapter, the roles which researchers, consumers, and practitioners assume throughout the search for a solution to a real problem in rehabilitation practice are emphasized and interrelated in concrete terms. This example demonstrates how this methodology can arrive at more meaningful solutions and applications of research in rehabilitation; in this case, by improving and sustaining rehabilitation counselor performance.

Discussion

The following example was constructed around the six stages and a presenting problem of "how to devise an equitable approach to counselor performance evaluation." The example shows how the methodology would play out with a real problem, how the three players function together, how the three bring about quality solutions to a real problem.

How does one involve consumers, practitioners, and researchers in developing, implementing, and using the results of such a study to impact on what is done to assess and improve performance? In the previous chapter, the unique functions of the "players" were discussed in general terms. Here, the functions which researchers, consumers, and practitioners can assume throughout the search for solutions to a continuing problem in rehabilitation practice are interrelated. The key players are explicitly identified. Consumers in the example include clients served by rehabilitation counselors, their parents, and/or guardians. Practitioners include vocational rehabilitation counselors, their field supervisors, and the agency administrator. Researchers include program evaluators, assessment-testing experts, and human resource development personnel.

Each player's participation throughout the process is based on their expertise in their self-defined roles. They each bring a unique view of what the focus should be in appraising counselor performance. They also bring experience and insight to the question of how counselor performance may be improved, and how to recognize and commend excellence in counselor performance.

While the discussion stresses what their roles add to the process, the reader must remember that no two consumers, practitioners, or researchers are alike. They come to the research-applications task with the unique skills, knowledge, and needs ascribed to their role(s), but those attributes have been shaped by personal experiences. The example attempts to provide the reader with some sense of the various ways the players might carry out their role.

What Is the Real Research Problem

What makes a rehabilitation counselor effective? What does "adequate performance" by a rehabilitation counselor look like? How are "better" and "poorer" counselors distinguishable from each other? What constitutes an equitable method for evaluating counselor performance? These four questions (and others like them) go to the heart of the rehabilitation process. Few people knowledgeable of the rehabilitation process would question the importance of this as a research topic. Few issues have raised as much concern, yet research has not produced clear and definitive answers.

What constitutes effectiveness in terms of a counselor's performance varies with one's perspective. To the counselor's immediate supervisor, it may be the number of successful closures obtained during a year or the distribution of people on the counselor's caseload. To consumers, it may be the counselor's availability, willingness to provide services, ability to understand their questions and needs, enthusiasm, and advocacy for them. To the researcher, both perspectives may be considered appropriate as the researcher is more likely to be concerned with the extent to which the reliability and validity of each of these attributes can be measured among all possible combinations of counselors: those trained on-the-job or in degree programs, among young and old counselors, among minority and non-minority counselors, between experienced and inexperienced counselors, between male and female counselors, among counselors with specialized and non-specialized caseloads, among counselors in Montana and in Florida.

The researcher and consumer may question what caseload size has to do with effectiveness of the rehabilitation process. Consumer and rehabilitation counselors may see counselor performance to be a function of the severity of the consumer's disability, the financial resources available to serve the caseload, the process consumers go through to become eligible for services, and a myriad of other factors. Most likely, as a group, consumers, practitioners, and researchers would envision a more complete sense or definition of "quality counselor performance" than they would separately. Such a composite definition would likely include a number of criteria which, in various combinations, would more fairly represent what it means to be "effective" as a rehabilitation counselor.

Their combined list of indicators might include criteria such as: responsiveness to consumer needs, completeness and quality of caseload management, closure patterns or rates, efficiency in use of available services, quality of rehabilitation plans, extent of consumer participation, and consumer satisfaction. After this list is refined and developed, the next stage of the research process, research planning, can proceed.

We Need a Plan

The roles of the players in the research planning stage may take on some unique functions. The researcher may intermittently serve as teacher for the consumer and the practitioner. In this role, the researcher may share information on prior research into counselor performance, teach them the standards of research methodology, and help them develop an awareness of the attention to detail the study will require. Practitioners, in turn, because they are more aware of the rehabilitation process, may contribute needed procedural and policy information which must be considered in planning the research and any subsequent action that will come about because of the research. They are likely to be a valuable resource on current methods used to assess counselor performance.

Consumers may initially serve as advisors to the other players. In this role they may share their knowledge of the problems consumers encounter, characteristics which are particularly indicative of appropriate counselor behaviors, and offer options which they see as ways to reward or improve counselor productivity. Later, as measures of customer satisfaction are sought or developed, consumers may screen, select, or provide input into how valid responses may be obtained from consumers; especially those who have been discouraged by the system or who are fearful of reprisal.

Together, researchers, consumers and practitioners may design the instrumentation and set acceptable performance levels for each of the criteria. Likewise, the three may identify how, in their particular roles, they may contribute to insuring maximum responses or from consumers, practitioners, and other relevant parties (e.g., employers, supervisors, co-workers). Consumers and counselors are probably best able to advise the team regarding how they would approach the rehabilitation staff to make the research effort more appealing, and to assure a better return on the research questionnaires. The researcher may be best able to take the ideas of the consumers and practitioners, incorporate them into a clear and concise research plan, and refine the research instruments (and later, the appraisal system). The three, together, can then evaluate the feasibility, appropriateness, sensitivity, and integrity of the research plan, associated data collection procedures, and analysis schemes.

Getting Answers

The practitioner and the consumer may not, at first glance, seem to have significant roles in carrying out the research. While it might appear otherwise, this phase is not the researcher's exclusive domain. The research involves a two-fold commitment shared by all three players: To increase the equity of counselor performance assessment, and to improve the performance of individual counselors on behalf of people with disabilities.

The value of this research will be limited by the extent to which large numbers of representative practitioners and consumers take part in the research. Its value will also be limited by the extent to which each of them participates as fully and consciously as possible. If the assessment mechanism is to effectively distinguish counselors performing more or less well, a representation of counselors from all levels of quality are needed to establish a baseline or standard for performance. If there is to be an adequate picture of what constitutes "good", "acceptable", and "unacceptable" performance among counselors across the dimensions the players have identified, the conscious participation of consumers is of paramount importance (e.g., in appraising their satisfaction, in defining appropriate and inappropriate instances of counselor behavior, in measuring the benefits achieved by individual consumers served by "good" and "poor" counselors).

Likewise, significant data are needed about the behaviors "poorly performing" counselors must acquire to be retained. The "poor" and "good" counselor should be clearly distinguishable. Ways to improve performance need to be identified and implemented as a matter of practice following appropriate research. It is, therefore, critical that consumers, counselors, supervisors, and relevant human resource personnel are fully engaged in the research to identify alternative experiences and skills which counselors must achieve if they are to be retained in the service of people with disabilities. Of equal importance and often overlooked in appraisal and performance improvement research, is the critical need to identify motivations for maintaining high levels of performance, including reward, recognition, and skill development.

These research and development issues require significant advocacy and participatory efforts on the part of each of the players in order to get significant involvement of their respective constituencies. Each may contribute to the research and be of value in contacting the "hard to reach subjects," in "talking-up" the importance of the project, in convincing their colleagues to make the personal investment necessary for the research to yield an appraisal system which is more balanced and likely to be more beneficial to consumers.

Making Sense of New Knowledge

As in the previous phase, it might at first seem that it is the researcher who has the skills, technology, and experience to aggregate data and reduce it to a form that addresses the most important issues of the research. True, the researcher does bring very unique skills to the research problem. He/she can offer well formed presentations of the information, especially in relation to the conventions of the rehabilitation discipline. A researcher's first analysis rarely provides all the illumination that the researcher might bring to solving a rehabilitation problem, however. Rarely does the researcher operate in isolation, merely applying statistical or other analytic principles to data, and deriving succinct unambiguous conclusions. In most instances, the analysis process is better represented as a process of applying a repertoire of tools, as might the craftsman, to identify reliable and most likely alternatives.

As might the consumer who seeks "an answer," or the practitioner who seeks stimulating alternatives, the researcher (even with significant input to develop the research) can contribute most when practitioners and consumers are involved in this analysis and interpretation phase. Some of the important research questions may be raised by the researcher, but more of those questions are likely to be raised as the researcher, consumer, and practitioner explore the research results from their individual perspectives.

The research results regarding counselor effectiveness may suggest characteristics of the counselor-consumer relationship that would at first appear illogical or to contradict conventional wisdom. The analysis of the data may suggest that counselors with the shortest job tenure produce the best case closure rates and receive high scores for client satisfaction, a result which contradicts conventional wisdom. The practitioner and the consumer may help the researcher gauge the importance of such a finding. Together, the players may recommend further analyses to understand why the clients are more satisfied with new counselors. These analyses may reveal that new counselors are more willing "to advocate on behalf of their clients" than are older counselors. The measure of counselor performance may, therefore, be skewed and not applicable for general performance appraisal, or may require norms specific to counselors with a certain number of years of employment within the system.

From a performance enhancement point of view, such results would suggest different actions with newer and older counselors. The more experienced counselors have become frustrated with policies, procedures, and resource availability and their frustrations are only temporarily alleviated by the individual counselor's personal energies. Practitioners, supervisors, educators, and consumers would each have high vestments for altering what may be the forerunner of a "burned-out" syndrome, rather than appraisal of a better performance among newer counselors. Where the new counselor may have the energy to go up against the odds, the counselor who has worked on behalf of people with disabilities year after year may need to acquire different or adapted skills. They may need to develop better coping mechanisms or be retrained to develop their personal techniques to build upon their "memory and experiences" in how to successfully use the system to access benefits for consumers.

These are not alternatives the researcher alone would likely develop. Without the input and involvement of the other players, the research would not ascertain whether the research data would provide support to such options.

Both consumer and practitioner are critical in guiding the analyses and interpretation and, therefore, may serve very important roles in developing a report from the research which defines meaningful applications. Further, they each very often have practical and innovative ideas concerning how to present information, findings, and recommendations which attract the attention of their constituencies. They can complement the researcher's capacity for guarded accuracy and help translate, highlight, and package findings in formats with particular interest and poignancy for their constituency.

Getting the Right Messages Out

All three players have special ways to "get the right message out to the right audience." This is dissemination. This requires the sythesization and packaging of the findings and alternatives which research suggests for practice before the products (i.e., the right messages) are marketed. Both the consumer and practitioner contribute their perceptions of the data as it relates to identifying strong rehabilitation counselors. They may use the information from the research and package it in ways that can be used by their constituencies to address their concerns about counselor performance.

Practitioner packaged findings. The package the practitioner might wish to promote would stress utility of the assessment in agency operations: availability of an equitable appraisal system, how the appraisal system would take place, the quality and value of the norms, the different kinds of interventions that might be recommended given different levels of counselor performance.

Consumer packaged findings. The package the consumer might market would be directed toward the system of rehabilitation and to other consumers: availability of a system for identifying incompetent counselors, behaviors to look for among the counselors they select, ways to demand internal applications and review of performance, how to advocate for changes in standards for counselor training.

Packaged findings for human resource development. The package the researcher (human resource individuals and measurement people are included in this example) would develop would be directed at human resource development: promoting development and human resource technology, competency-based learning, instructional mechanisms for enhancing and sustaining the quality of individual counselor performance.

The researcher is aware of some avenues for dissemination of the report, often journals, newsletters, conferences. The consumer and practitioner know other individuals, advocates, and personnel who could make use of the research (e.g., report, an interpretation). As a team, they may construct a mailing list of people most likely to make use of the findings. Individually, they will construct lists of contacts and sources which can make the greatest use of the information. Rather than trying to disseminate a report to as broad an audience as possible, the dissemination may be very targeted to individuals and groups which influence or control resources to achieve use of the appraisal methodology in state agencies.

Putting the Research to Work

Above, all three were synthesizing from a common profile of an effective counselor and bringing that profile back into terms meaningful to the reason they became involved in the process to begin with: To solve a rehabilitation problem. Each, in synthesizing, and in cross-checking and support for other applications, are in effect making the research applicable. All three make more use of the outcomes of research on counselor performance and may achieve its transfer to practice in this way. All three, of course, remain conscientiously attentive to the integrity and limitations of the research findings.

Knowledge gained from a thorough study of counselor effectiveness might also be transferred to other helping professionals. The consumer and the practitioner may be most qualified to identify "generic" characteristics which make for an effective personal attendant or rehabilitation technician.

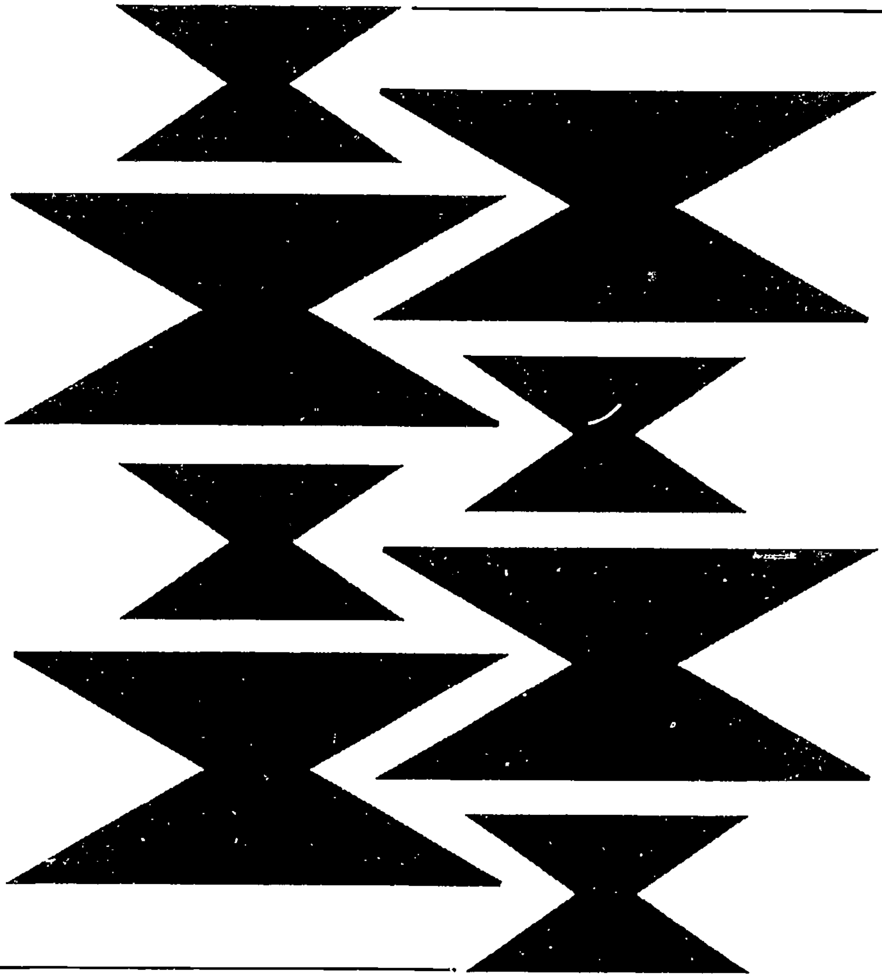
The three players may also direct the implications of the project to finding unique and better ways to employ, retain, and promote excellence in counselor performance.

Regardless, all three are prepared to market and advocate for the utilization of the research among their colleagues and contemporaries. Each can become an advocate for the research-driven-application within their constituency: The practitioner will bring something back to the agency that really works and is fair to individual counselors; the consumers are now able to demand better counselor performance because they are armed with accurate information about what is and is not possible; the researcher is now able to advocate for curricula and human resource development which are synchronized with professional and consumer expectations of counselors, and which are tied to a reasonable appraisal process.

Conclusion

Up to this point the text has attempted to help the reader envision two things: first, how research can be improved to produce a higher yield and, second, how better solutions to problems important to disabilities can be solved through a participant-inclusive research methodology. An example has been used to show the reader how alternative solutions to real problems can be solved using the participatory processes the IRI Study Group has identified. In the next chapter the Study Group concludes with specific recommendations for effecting system changes by involving those to be affected throughout the research and development processes.

Future Directions and Recommendations for Consumer Involvement



CHAPTER VIII

Future Directions and Recommendations for Consumer Involvement

Paramount to the success of achieving this common ground is the development of a strategic plan by all parties involved. This plan must outline the process, allow for financial implications, and assign priority to participation in research endeavors. The Study Group, in reaching this conclusion, has identified the following recommendations for all players as they embark upon this challenge through the strategic planning process:

1. Communication barriers must be overcome. To achieve maximum input, group facilitation skills should be developed using trained facilitators. Solutions to problems can and do come from those with personal involvement with the issues. Therefore, researchers and practitioners must become acutely aware of what is being said, and how to interpret the "real" message. Professional language and jargon should be left out of the process, providing openness and clear feedback to participants. Both the intended and the received messages should be the same, and this should be validated by an evaluation of the contents of the received message. Communication is vital, and techniques that include sensitivity to the needs of persons with disabilities should be developed, while also allowing for the diversity of the groups involved.

2. Resources must be budgeted for education and involvement of all participants. Successful participation in the process is often dependent upon recommendation for the participants. Individuals with disabilities must be provided with the financial means needed for their participation. Extra expenses, such as transportation, lodging, and attendant care, place an extra burden on these consumers and actually precludes participation by many.

3. Increased funding is needed for research and training center in vocational rehabilitation (which includes all programs such as independent living, supported employment, etc.). Investment in research must occur in order to effectively and efficiently respond to the varied needs of people with severe disabilities. Researchers should respond with increased sensitivity to the identified needs, regardless of the popularity of the topic. Also, agencies must commit funding and resources explicitly for research and development of best practices.

4. Practical ADA compliance issues must be resolved to provide access to people with disabilities. Information and technology should be in accessible formats (i.e., braille) and appropriate to the needs of the group for whom it was designed. IF any restrictions are imposed, the reasons for doing so must be fully explained to the participants.

5. Research findings should be adopted and applied in practice. Implementation of the research results that may include new techniques, incentives, or mandates will require funding. Transfer of application must occur upon completion of the research project, and clear definitions of best practices must be given. Findings must also be marketed outside the closed circle of involved participants. Simply acquiring the information is not enough, the central idea is to apply it through documentation into best practices.

6. Information on research and development projects must be disseminated to the public, and especially to consumers and practitioners. The National Institute on Disability and Rehabilitation Research (NIDRR) should reestablish a publication summarizing activities of all research and training centers across the country. Further, a national mailing list of advocacy groups should be compiled and used for announcements of NIDRR research and development projects. Finally, agencies, researchers, and practitioners should educate staff about the availability of resources (such as IRI documents) and the value of using these publications and findings.

7. Priorities for federal and state rehabilitation initiatives should be given on the basis of significant consumer involvement. Both the federal and state agencies (and their minions) should adopt in principle and in practice the "consumer involvement" model proposed in this document. The National Rehabilitation Information Center (NARIC) and other relevant clearinghouses should introduce coding for research and planning documents to index consumer involvement methods.

8. Collaboration and coordination between NIDRR, Rehabilitation Services Administration (RSA), and Council of State Administrators of Vocational Rehabilitation (CSAVR) is of utmost importance in placing "common ground" principles into practice. A national panel or council of federal agencies for priority setting, truly representative of the researchers, practitioners, and consumers should be formed. Accountability standards for state and federal programs should include performance indicators to measure the extend to which consumer involvement has become an integral part of their planning and development. Further, a system should be developed for providing feedback to the consumer advisory committees used in the accountability process. Other organizations and offices, such as mayors' offices, should be provided information and offered invitations to participate in the procedure to increase awareness of the consumer involvement process and ensure integration into the system. State vocational rehabilitation agencies should form a planning section to develop an implementation format for using the information gained from research.

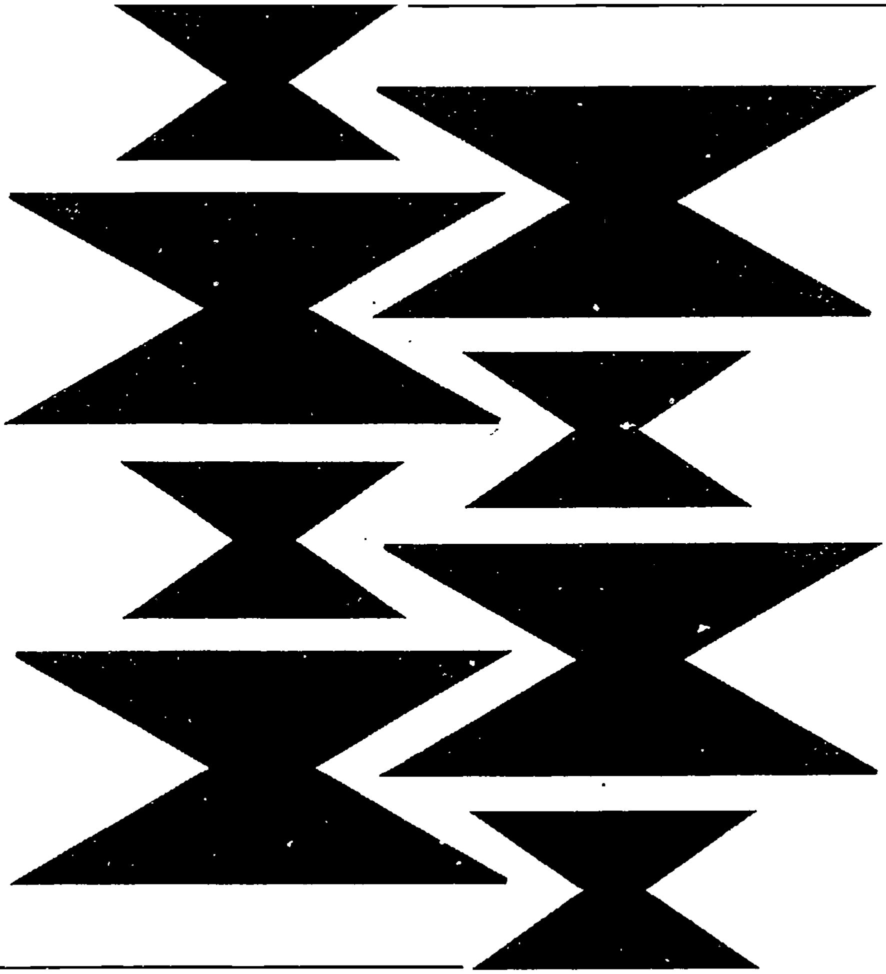
9. Training should be conducted for researchers, practitioners, and consumers to emphasize behavioral and language changes such as use of words like "we" instead of "me" or "you" to denote shared responsibility. Training should be provided to educate vocational rehabilitation and client assistance program staff about the IRI process, all IRI documents written, and all other important research projects. Trainers in vocational rehabilitation, client assistance programs, independent living centers, etc., should dispense this information to the local offices. CSAVR needs to develop a communication system to increase participation in the IRI program by including more facilities in the planning and procedures process.

10. When changes are imminent, professional commitment should be made at all levels to become involved, innovative and practice, rather than having the change process control us. This learning process is vital. We may not be able to do anything about the past, but we can do something about the future.

11. CSAVR should develop a mechanism for using research, and should take the leadership role in influencing the formulation of federal policies that develop a system for the use of research and education.

12. Title I Research should be a part of state vocational rehabilitation budgets, and legislation should be translated into policy to permit state agencies the use of money for research.

Although consumer involvement is not a new concept, it is still an unresolved issue because consumers have never been successfully blended into the rehabilitation research and practice process. The successful integration of consumers in rehabilitation research and practice depends on the provision of professional training and technical assistance, because consumers need assistance in developing the skills required for successful interaction and participation. Consumers, researchers, and practitioners must strive to obtain the information necessary for the successful implementation of a cooperative working relationship.



APPENDICES

Appendix A

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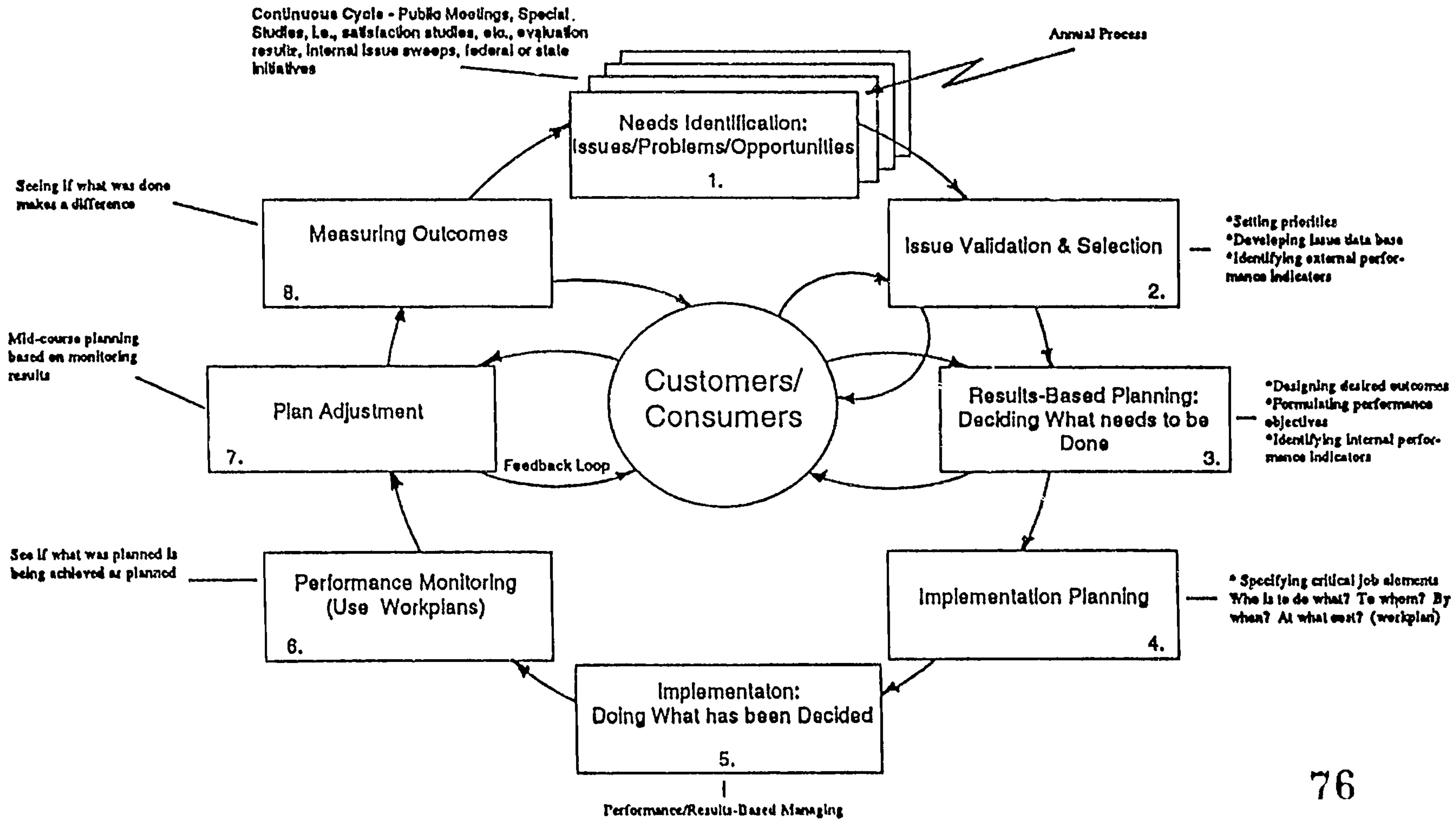
Appendix C

A Continuous Improvement Planning/Implementation Process Model

(Market-Driven - Customer-Responsive - Performance/Results-Based Planning)



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