DOCUMENT RESUME

ED 365 695 TM 020 869

AUTHOR	Becker, Heather
TITLE	Values, Stakeholder, Structure, and Measurement Challenges in the Evaluation of Disability Programs.
PUB DATE	Nov 92
NOTE	8p.; Paper presented at the Annual Meeting of the American Evaluation Association (Seattle, WA, November 5-7, 1992).
PUB TYPE	Viewpoints (Opinion/Position Papers, Essays, etc.) (120) -- Speeches/Conference Papers (150)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Community Services; *Delivery Systems; *Disabilities; Evaluation Methods; *Evaluation Problems; *Measurement Techniques; Program Effectiveness; *Program Evaluation; Program Implementation; *Values
IDENTIFIERS	*Service Delivery Assessment; Stakeholder Evaluation; Value Orientations

ABSTRACT

Challenges faced in the evaluation of programs for the disabled are discussed, focusing on values orientation, key stakeholders, program structure, and measurement issues. Workers in the field are presently witnessing a fundamental change in the philosophy that underlies programs for persons with disabilities. Evaluators must be sensitive to the values orientation behind each program. Disability programs have multiple stakeholders, and an evaluator must identify key stakeholders and be responsive to consumers and their families. The shift toward community-based services is having an effect on program structure, and is increasing the number of small programs without the established hierarchical structure of larger human services programs. A final consideration is the measurement of program outcomes. Acknowledging multiple perspectives will require finding or developing multiple measures of program outcomes. These are exciting times for programs that serve persons with disabilities, but these advances require improved evaluation to ensure the best service delivery possible. (Contains seven references.) (SLD)

VALUES, STAKEHOLDER, STRUCTURE, AND MEASUREMENT CHALLENGES IN THE EVALUATION OF DISABILITY PROGRAMS

A paper presented at the American Evaluation Association

November 5, 1992

Heather Becker, Ph.D.
Texas Consortium for Developmental Disabilities
The University of Texas at Austin

The paper I am presenting today came out of my work in developing an evaluation resource guide for programs that serve persons with developmental disabilities. My consultant for this project was Karen Kirkhart, another presenter in this session. As we talked to program staff and examined the literature in this area, we became away of contextual issues that pointed to important challenges for those of us who evaluate disability programs. We don't mean to imply that these challenges are unique - evaluators have certainly encountered many of them before - but they are certainly worthy of consideration by those who are evaluating disability programs, particularly those in adult services.

First, a little background in this area. According to the Developmental Disabilities Assistance and Bill of Rights Act of 1990, the number of individuals with developmental disabilities in the United States is more than three million. People with developmental disabilities are defined as those who acquire their disability before age 22, so this number fails to include all those who become disabled as adults. Programming for persons with disabilities is administered through providers in the education, rehabilitation, health and human services sectors, as well as from many private non-profit agencies, such as United Way or United Cerebral Palsy Associations.

I have identified four contextual issues that characterize the current climate in disability services which I would like to discuss today. These issues are: values orientation, key stakeholders, program structure, and measurement issues.

Values Orientation

We are witnessing a fundamental shift in the philosophy that underlies programs for persons with disabilities. In the last century, the focus was on custodial care, with value on safety and security within institutional settings. About 20 years ago, there was a shift to a focus on skills building and preparing people to live and work in sheltered community settings. Evaluations of these programs emphasized the extent to which clients were mastering new skills and behaviors. In past decade or so, Knoll (1991) pointed to a new paradigm shift . Many advocacy groups now argue that an individual with disabilities, no matter how severe his impairments, should be able to be fully included in normalized community living.

Community integration, empowerment, full inclusion in regular education, and quality of life have become the watchwords; however, the best way to achieve these goals is still hotly debated among consumers, advocates, clients, service providers, and funders. These strongly held values, and debate about how best to meet them, have significant implications for evaluation. Certain outcomes will be more highly prioritized than others, and some of these outcomes , such as improved quality of life, are extremely difficult to measure, as we will discuss presently.

Programs aimed at transitioning special education students into competitive employment in their communities provide one example of the complex values issues that can accompany programs for persons with disabilities. Callan (1986) has pointed out that because these programs extend into the workplace, they must deal with the often unexplicated community corporate and marketplace values. Program directors are confronted with value questions such as :

a) Should greater job preparation efforts be directed at those with the most or least severe disabilities?

b) Can subsidized employment to persons with disabilities be justified when non-disabled workers are competing for the same jobs?

While there are no easy answers to these values questions, Callan argued that part of our responsibility as evaluators is to define issues in ways that enable decision-makers and other program stakeholders to arrive at more sophisticated, if not less troubling, understandings.

Whatever debate exists about which outcomes are most important and how best to meet them will be played out in the evaluation. These differences require evaluators to be extremely sensitive to the context in which programs exist and the diverse constituencies involved. This brings us to the second issue: Key Stakeholders.

Key Stakeholders

While most evaluation situations have multiple stakeholders, disability programs **really** have multiple stakeholders. I was recently appointed to the advisory group overseeing the evaluation of the process of closing two state schools in Texas. This study was commissioned by the state MHMR, who is the primary stakeholder. However, I counted 13 other stakeholder groups: local administrators in the two state schools; employees; private providers in the community who will receive some of the clients; other state schools who receive other clients; the regional community mental retardation authorities who now become responsible for the clients ; service providers in other agencies; local government officials whose economy is impacted by the closure; the Governor who is still under fire for deciding to close the two state schools; state legislators who are being pressured by some constituencies to reverse the decision; clients themselves; their families; advocacy groups, some of whom want all schools closed and others who want all left open; and last, but not least, the legal system, since the closure is part of a court settlement. An evaluator could develop whiplash, simply trying to listen to all these diverse groups!

Clients with multiple handicapping conditions, particularly those acquired early in life, have many complex needs. Consequently, programs that work with them often find themselves coordinating services with other providers. An adult client who is deaf and blind may need employment services, residential services, health services, and all these services may be provided by different agencies. This coordination effort in itself may call for certain evaluation activities and may also facilitate the sharing of information which can be useful to the program's evaluation effort.

Evaluation has an increasingly critical role to play as persons with developmental disabilities move out of institutions into community settings. Dufresne (1990) pointed out that many parents oppose deinstitutionalization because they believe institutions provide a safer place to monitor the quality of services than do decentralized community environments with multiple service sites. Evaluations that are responsive to these concerns and demonstrate the safety and quality of community services can go a long way toward alleviating family fears during this transitional period.

One of the most deeply held values in many disability programs is that they should be "consumer -driven". This implies a greater role for consumers in program evaluation than simply responding to data collection activities. Evaluators of programs that serve persons with disabilities will therefore be challenged to involve consumers and families in the planning and interpretation of evaluations of **their** programs.

Program Structure

The shift in emphasis to community-based services has had its effects on program structure, as well. These programs are often small. Group homes, for example, usually serve less than a dozen clients, and many in the disability community are calling for smaller, more home-like supported living arrangements, with four residents or fewer. Staff in these programs may consist of a couple of administrators or program managers and a small direct care staff, although they may be attached to larger, parent organizations which provide much of their administrative infrastructure and oversight, and are funded largely by huge departments for human resources. In many cases, the paid staff is augmented by volunteers, who assist the clients on a daily basis. Many of the programs, particularly those involving residential services, are administered by private funders. Such programs frequently lack the established hierarchical structure of other human service programs, such as those in education; when there is only direct service staff and a couple of administrators, there just aren't that many layers of bureaucracy.

This structure has important implications for evaluation. Because there are fewer levels of bureaucracy, information may pass more freely through the program's informal communication network than it might in a larger organization. In this environment, evaluation may provide empirical validation for what staff already perceive is happening in the program. On the negative side, fewer resources may be available for planning and carrying out the evaluation. Bradley and Bersani (1990) pointed out that given the pluralism and dispersion in community-based services, there won't be enough state employees to handle all monitoring and quality assurance . Advocates, case managers, and people with disabilities will have to take increasing responsibility for these activities. Evaluators will be challenged to include them in the evaluation process - not only as targets themselves of evaluation, but also as data collectors and decision-makers about what to evaluate.

The emerging community integration model promotes individualized outcomes and choices and really calls into question how programs are to be defined. Even how we label those who receive services has been redefined; many prefer to be called "consumers" rather than "patients" or "clients". This paradigm shift raises interesting questions for evaluators. If we are moving away from structured programs that deliver clearly defined services, to a consumer-driven support system, then evaluation approaches dependent on standardized service-delivery models in which all clients receive the same intervention simply will not fit. Instead we must develop approaches that are responsive to individually determined needs and outcomes.

Measurement Issues

Many of the outcomes of interest to programs for persons with disabilities are elusive and difficult to measure. For example, quality of life issues are becoming increasingly salient. However, quality of life confronts us with a challenging measurement problem, since quality of life is hard to define, let alone quantify. Definitions of this complex construct vary greatly. Looking at quality of life issues from a health care arena, Caley (1991) identified three different perspectives on quality of life. Consumers tend to define it in terms of (a) responsiveness to perceived care needs, (b) level of communication, concerns and courtesy, (c) degree of symptom relief, and (d) level of functional improvement. By contrast, professionals tend to emphasize the degree to which care meets the current technical state of the art and freedom to act in the full interest of the patient, while purchasers of services are concerned with efficient/appropriate use of health care resources and maximum possible contribution of health care to reduction in lost productivity. The point here is that perspectives on quality of life vary. While there are many tools that purport to measure this construct, the issue becomes whose definition of quality of life should be used? If we are serious about supports/services tailored to the needs and desires of consumers, then we will need to use their definitions - and find or develop measures that fit these definitions.

Feedback from clients about their satisfaction with services is an important component of many evaluation systems. Such information is usually collected orally or in writing. But programs that serve persons with disabilities face some special challenges in collecting information from clients who have limited communication skills. Clients who do not read cannot complete most written evaluations, although it may be possible to use pictures instead of words. For example, clients can be asked to select from a series of faces with expressions depicting various degrees of happy and sad affect to indicate how they feel about certain situations. Other clients may be unfamiliar with the concepts of choice or intrapsychic phenomenon (e.g., self-actualization) that are often the focus of our self-report measures. In the past, we have often dealt with this problem by interviewing parents or advocates, rather than the clients themselves. However, as clients take a more active role as partners in the service delivery system, it becomes increasingly important that we find ways to communicate directly with them about their needs and preferences. In so doing, we must establish that any self-report measures we use with clients have meaning for them and are presented in a way to which they can respond. To that end, Biklen and Moseley (1988) and Sigelman, et al. (1981) describe carefully constructed interview studies with clients who are mentally retarded.

The outcomes of many human services programs target positive client change. We look for increased reading skills in education, or acquisition of jobs by unemployed persons, or better utilization of health care services. However, in many programs that serve persons with disabilities, particularly adults, the critical goal may be maintenance of current functioning, or in the case of clients with degenerative impairments, a decrease in the trajectory of declining functioning. Unlike programs that aim to make relatively short-term gains for clients and have them then leave the program, many of these clients will be with us a very long time. For example, a volunteer advocacy program may have as its goal providing enough support to clients to enable them to continue living in community settings. In this situation, the goal isn't progress, but maintenance of the ability to live independently in the community. We therefore need to recognize that maintenance can be a significant outcome, and consequently measures that assess stability, rather than change, must be developed. In addition, longitudinal data analysis will become more important to us.

Conclusions

In conclusion, these are exciting times for programs that serve persons with disabilities. For example, the passage of American with Disabilities Act this year is removing many barriers that have kept people with disabilities from participating fully in community life. With these opportunities come challenges to the programs that serve these individuals to meet their needs for integration and quality of life more effectively. What this means for evaluation is that we are increasingly called on to find ways to determine the effects of new and innovative service delivery mechanisms. I would encourage you all to take up the challenges I have touched on today to design evaluations that meet the needs of these programs.

References

Biklen, S.K. and Moseley, C.R. (1988) "Are you retarded?" "No, I'm Catholic": qualitative methods in the study of people with severe handicaps. The Journal of the Association for Persons with Severe Handicaps, 13(3), 155-162.

Caley, L. M. (1991). Issues in an interdisciplinary approach to clinical outcomes evaluation. Paper presented at the Annual Meeting of the American Evaluation Association, Chicago, Illinois.

Callan, J. (1986). Evaluation, societal values, and transition programs. In R. E. Stake (Ed.). Issues in Research on Evaluation in Transition. Champaign, Ill: Transition Institute at Illinois.

Defresne, D.F. (1990) The role of service providers in quality assurance, in V.J. Bradley and H. A. Bersani (eds) Quality Assurance for Individuals with Developmental Disabilities. Baltimore: Paul Brooks.

Knoll, J. (1991). The support paradigm and persons with disabilities. Paper presented at the Annual Meeting of the American Association of University Affiliated Programs for Persons with Developmental Disabilities, Austin, Texas.

Sigelman, C., Schoenrock, C. J., Winer, J.L., Spanhel, C.L.; Hromas, S.G., Martin, P.W.; Biudd, E.C., and Bensberg, G.J. (1981). Issues in interviewing mentally retarded persons: an empirical study. In R. Bruininks, C. Meyers, B. Sigform, and K. Lakin (Eds.) Deinstitutionalization and Community Adjustment of Mentally Retarded People. Washington, D.C.: American Association on Mental Deficiency.

University Affiliated Programs. (1989). National information and reporting system: 1988 report. Silver Springs, Md: American Association of University Affiliated Programs for Persons with Developmental Disabilities.