

Measuring Cost and Effectiveness from a Consumer Perspective

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Three Perspectives

Cost effectiveness studies are designed to relate the costs of program delivery to the effectiveness of the program in order to assess which programs offer the most impact per unit of cost. The methodology for such studies was originally developed for the purpose of justifying expenditures for large federal projects (initially dam construction by the Army Corps of Engineers) and was most often performed from the administrative perspective. More recently, cost-effectiveness analyses have become a standard component of health services research. Although there is wide agreement that this type of analysis is important, few standards of cost-effectiveness procedures have gained wide acceptance. Certainly there is greater consensus on methods for defining costs than on methods for defining effectiveness.

With regard to effectiveness, much of the work in health services can be found in the quality of care literature. There, three major perspectives are represented: the consumer's, the provider's, and the administrator/policy maker's. To date, research which is described as from the consumer perspective primarily focuses on the nature of the relationship between the consumer and the provider (i.e., whether the provider does what he/she says will be done). Technical quality, or performance of procedures within professional standards, is the primary concern from the provider perspective. Administrators generally focused on efficiency or cost-effectiveness. The perspectives can be used for both cost measures and effectiveness measures. However, cost measures are typically developed from the administrator's perspective and effectiveness measures tend to use some combination of the consumer's and the provider's perspectives.

The most inclusive study of cost-effectiveness would include separate effectiveness criteria developed by consumers, providers, and administrators as well as measures of outcomes, the processes leading to those outcomes, and the organizational structures within which the outcomes are attained. Measures of cost would also take into account costs to the consumer and "loss of opportunity" costs. Fiscal constraints placed on the evaluation component often demand a more limited focus and the consumer perspective

of cost and effectiveness is often dropped.

What Is at Stake

If decisions about retaining, dropping, or altering programs are to be based on cost-effectiveness studies, given that those studies relate costs of program delivery to the effectiveness of the program - seeking the most impact per unit of cost - it is critical that measures of cost and effectiveness accurately reflect the impact that the program has on the individuals receiving the service. This is especially true in a political atmosphere which is examining the cost effectiveness of all publicly funded programs with a primary goal of cutting programs. The disability community at large has a high stake in assuring that cost and effectiveness are measured from a consumer perspective.

Traditional cost-effectiveness measures have typically failed to capture the important aspects of how services affect the lives of the people they are intended to serve. While people with disabilities, providers, and administrators are all concerned with the same issues (costs, accessibility, the relationship between the provider and consumer, amount of control and direction, safety, reliability, etc.), they may differ in the relative weight they give each issue in developing measures and interpreting results.

Assuring Authentic Consumer Perspective

How can cost and effectiveness measures more accurately assess the extent to which programs are "cost-effective" from the perspective of people with disabilities? Using a participatory action research (PAR) approach is important to the development of cost-effectiveness criteria from the consumer perspective. PAR involves including the stakeholders in all phases of the research from the development of the criteria and evaluation instruments to the interpretation of the results. The criteria will then accurately reflect the important aspects of cost and effectiveness from the perspective of the consumer. The content of cost-effectiveness measures will be different depending on who is involved in the development of the measures. For example, consumer driven cost measures of personal assistance services (PAS) might take into account work disincentives and the emotional costs of PAS programs. Effectiveness measures might focus on the "instrumentality" of the program, i.e., does PAS enable me to do what I want, or interfere?

The World Institute on Disability has developed a measurement of effectiveness of PAS from the perspective of consumers. Through an

exhaustive literature search, including both academic and "fugitive" literature, and a series of focus groups with consumers, a list of consumer criteria for effectiveness was developed. This list was used to develop a questionnaire designed to measure effectiveness which is currently being validated. The survey includes measures of: 1) who can deliver the services, 2) what the services include, 3) where the services can be used, 4) when the services can be used, and 5) how the services are delivered. In addition, there are measures of the amount of choice and consumer direction in each of these areas, the costs to the consumer, and satisfaction with the services. Information from consumers is being collected and will be aggregated with program information to examine cost effectiveness.

An issue that needs addressing is how to develop consumer-based measures for people with cognitive and developmental disabilities. The perspective of individuals with cognitive disabilities is often left out because it is assumed that their responses would jeopardize the reliability and validity of the surveys. While many with cognitive disabilities lack the reading and writing skills necessary to complete a research questionnaire, they may have communications skills sufficient to answer appropriately stated interview questions. Yes/no and either/or questions are more reliable than Likert type and open ended questions, although they are more subject to acquiescent responses. Responses to questions about activities and objective events are likely to be accurate and reliable, while questions about feelings, causes, and time are less reliable. Current research is examining whether telephone interviews yield reliable responses.

To conclude: Since cost-effectiveness analysis is an important part of the development and implementation of all service programs, it is important that the measures for evaluation and quality of care accurately reflect "quality" and "success" from the consumer's perspective and further that the measures reflect the heterogeneity of the consumers being served.