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Assessing Disabilities and Planning Services

Do not do unto others as you would they should do unto you. Their tastes may not be the same.

—*George Bernard Shaw*

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INTRODUCTION

Basic to the development and use of technology are the procedures by which disabilities and handicaps are identified, goals are established for their elimination or reduction, and resources are expended. This chapter addresses: 1) the methods for accomplishing the first two of these three functions, 2) the extent to which these methods are effective in providing information to aid the third function of allocating resources for the lessening of handicapping and disabling conditions, and 3) the extent to which these methods may be used efficiently, since they are themselves costly.

The assessment and planning methods (or procedures) in the disability area can be considered parts of a systems technology. The effectiveness of this system should be measured by criteria that are important to and determined by the users of the system. The primary users of the assessment and planning system, from the perspective of this study, are Congress and the Federal agencies concerned with the allocation of public funds. This chapter, therefore, examines the degree to which data provided by the assessment and planning system are useful to or effective in public policy decisions. After focusing on the effectiveness of the systems in generating such data, the chapter presents a methodological discussion of the techniques for identifying and assessing impairments, disabilities, and handicaps. The chapter also discusses the degree to which the data collection procedures are or might be useful to the individual

participants in the assessment and planning process.

The major laws dealing with the treatment of disabled persons in three areas will be reviewed:

1. the portion of Public Law 95-602 (the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978) dealing with vocational training and rehabilitation,
2. the portion of Public Law 95-602 dealing with developmental disabilities, and
3. Public Law 94-142 (the Education of the Handicapped Act), dealing with the education of disabled children.**

The objectives of the assessment and planning system are to provide data for the following: 1) determination of eligibility for services, 2) determination of services required, and 3) evaluation of the effectiveness of services provided. The next section of this chapter examines these three goals, from the perspective of the assessment and planning system's actual or potential effectiveness in providing data for policy decisions. The section following that examines them from a methodological perspective.

*This chapter is based on a paper presented for OTA by Dr. Mark Ozer of the George Washington University School of Medicine.

**● An overview of legislation in this area is presented in app. B. Also, a note on terminology: Many of the statutes in this area use the term "handicapped" instead of "disabled" in places where the latter term would be more appropriate, according to OTA's definition scheme. OTA uses the terms of the legislation only in quotes from those laws.

MEASURES OF EFFECTIVENESS

The measures of the assessment and planning system's effectiveness are based on the objectives of the data collection system as determined by the laws relating to disabilities.

Determination of Eligibility

The first objective of the assessment and planning system is the collection of data to determine eligibility for services. Each law addressing disabilities has required that services be provided to the appropriate persons. Although definitions of which individuals are entitled to services vary, in every instance some determination must be made of the presence of disability.

Eligibility for vocational training and rehabilitation under Public Law 95-602 (Rehabilitation Act of 1978) is defined as follows [sec. 7(7)(A)]:

The term "handicapped individual" means any individual who (i) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment and (ii) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services.

There is a requirement under this law to deal with the needs of "severely handicapped" people, and "severe handicap" has been given the following definition [sec. 7(13)]:

The term "severe handicap" means a disability which requires multiple services over an extended period of time and results from amputation, blindness, cancer, cerebral palsy, cystic fibrosis, deafness, heart disease, hemiplegia, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia, and other spinal cord conditions, renal failure, respiratory and pulmonary dysfunction, and any other disability specified by the Secretary.

Eligibility for services for developmentally disabled persons under Public Law 95-602 shares the basic requirement of an impairment of a physical or mental nature but defines more functionally the areas of disability that may occur as a result of such an impairment [sec. 102(7)]:

The term "developmental disability" means a severe, chronic disability of a person which (A) is attributable to a mental or physical impairment or a combination of physical and mental impairments; (B) is manifested before the person attains age twenty-two; (C) is likely to continue indefinitely; (D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and (E) reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned or coordinated.

This definition also extends to the severity of the problem in that it is long lasting and starts prior to adulthood.

The eligibility criteria in Public Law 94-142 (Education of the Handicapped Act) establish the need for special educational services on the basis of multiple evaluations in several functional areas by multidisciplinary teams as follows [sec. 12a5] (Federal Register, Aug. 23, 1977):

The term "handicapped children" means those children evaluated . . . as being mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, orthopedically impaired, other health-impaired, deaf-blind, multi-handicapped, or as having specific learning disabilities, who because of these impairments need special education and related services.

At first glance, this definition is the least functional of those presented so far, but it is amplified in the regulations, which further define each category, so that it is at least equal to the others in its functional orientation.

In all three laws, there is a requirement for documentation of impairment and functional limitations resulting from such impairments. An administrative decision must be made regarding the presence of "disease." The data from such disability determinations can be used in individual cases to justify the expenditure of public funds for

disability-related services. These data are a prerequisite for accountability, but they have only limited value for the determination of appropriate services for individuals or for any specific category of persons.

The prime function of such determinations is to document the presence of impairments. One measure of the effectiveness of the assessment and planning system, therefore, is the degree to which data might be generated on the incidence of such impairments in the population. Such data would presumably be valuable to States and Federal agencies for more rational planning with respect to the amount of resources necessary for various categories of impairment.

The State plans required from each State to establish eligibility for Federal funds under Public Law 95-602 do require reports that include estimates of the disabled individuals requiring services, with particular emphasis on those with most severe disabilities. The law also requires estimates of service costs for such categories. Furthermore, it requires continuing statewide studies of the needs of handicapped individuals and how these needs may be most effectively met . . . with a view toward the relative need for services to significant segments of the population of handicapped individuals and the need for expansion of services to those individuals with most severe handicap" [sec. 101(15)].

The requirements for identification of disabled children under the provisions of Public Law 94-142, in order to assure accountability in Federal reimbursement, are very specific. The State education agency is required to report data on the numbers of disabled children within each category of disability and their age distribution [sec. 121a.751]. However, the data are frequently inaccurate, and the estimates of the numbers and types of disabilities are considered to be highly unsatisfactory. Many children are incorrectly classified as disabled; others possess undetected disabilities. There is wide variation in the criteria used to assess the severity of a disability. Children, particularly those from minority groups, are often falsely identified as having impairments (109).

In fulfillment of Public Law 95-602, a component of each State's evaluation system for developmental disabilities specifies a requirement for "client identification and demographic data" [sec. 110]. This includes age and sex, ethnic group and income level, as well as whether the person is living in an urban or a rural setting. Data are to be collected on the type and degree of impairment based on various assessment scales (145). Unlike data collected under the requirements of Public Law 94-142, such data are collected in a variety of functional *areas*, reflective of the definition of developmental disabilities in the law. The definition in Public Law 95-602 does not mention categories in terms of "disease" entities as does Public Law 94-142. Furthermore, the data collected under the former law, in contrast to the latter data, are not primarily to be used for determination of eligibility for programs or for reimbursement of service costs, but rather for purpose of evaluating comparable effectiveness in terms of "case mix."

Determination of Services Required

The second major objective of the planning and assessment system is the collection of data for the planning of appropriate services to persons who are deemed eligible. The evaluation process designed to determine eligibility has been expanded to deal with determining the specific problems of individuals and establishing plans for services.

In the area of vocational rehabilitation, Public Law 95-602 specifies that the evaluation to determine "rehabilitation potential" should be not only a component of the determination of eligibility but also a part of an individualized written rehabilitation program (IWRP). The IWRP specifies the services and technologies to be provided to the individual and also the goals for the use of those interventions (see the technical addendum to this chapter for those specifications).

The law relating to developmental disabilities as amended most recently (Public Law 95-602) has comparable requirements for the development of a habilitation plan for each developmentally disabled person (see the technical addendum to this chapter).

Like the requirements for vocational rehabilitation, but unlike the requirements for developmentally disabled individuals, Public Law 94-142 deals with the character of the evaluation procedure in some detail. It also deals with the character of the individualized educational programs (IEPs) to be developed for each disabled child. Comparable requirements for parental participation are highly specified (see the technical addendum to this chapter for the law's language relating to IEPs).

In these three laws, the procedures required for data collection have moved beyond the categorization of impairments alone. The evaluation process is now concerned with sampling functional capabilities in a variety of areas so as to lead to a rehabilitation program plan for each individual disabled person.

Despite the focus on the assessment of function rather than impairments, each such assessment is usually carried out in a framework of expected "norms" or standards. That is, the determination of the existence of a problem is generally derived from tests and other evaluation instruments that have been standardized in "normal" populations. Thus, data are collected on the areas of function in which the person is to be considered "deviant." These findings are translated into a set of "remedial" objectives and can be used to justify why any particular set of objectives has been chosen.

Even though such procedures may be a prerequisite for accountability of the objectives, they have limited value for the determination of the actual objectives that should be established for any individual. The data derived from the behaviors sampled on standardized tests frequently lack specificity as to the day-to-day problems that should affect the objectives set for individuals.

Because the prime function of such problem identification is to establish a rehabilitation program plan, one measure of the effectiveness of the assessment and planning system is the degree to which data have been generated for use in determining and planning *appropriate* services. The decision regarding which services to use and to what degree is a crucial one; assuring the appropriate use of technologies—both services and devices—for each individual is one of the critical

goals of an effective assessment and planning procedure.

Although data could potentially be generated on needs for technology and other services, an analysis of the various laws and the regulations to implement them indicates that the generation of such data remains highly unlikely at the present time. Only in the case of the portion of Public Law 95-602 dealing with developmental disabilities is the evaluation system to be implemented directly linked to data derived from the habilitation plans. One of the components of each State's reporting system is to include "service characteristics." Included in this category are data on each service received in terms of hours of service, frequency, type of provider and professional level of provider. In addition, each service planned for (or required) but not rendered is to be categorized as to its being scheduled (awaiting an opening or some other reason) or not available (due to "lack of funding" or "no appropriate service"). In this highly developed system, clear potential exists for the collection of information on the needs, both met and unmet, for services and other technologies (145). The developmental disabilities evaluation system is not yet in place throughout the country and has met with considerable resistance by a number of the States.

Determination of the Effectiveness of Services Provided

The third major objective for the assessment and planning system is the collection of data that could be used to evaluate whether services and other resources expended have been effectively used. This objective has been reflected, at least in part, in the ongoing evaluation provision within each of the laws discussed in this chapter. Some measure of outcome is required in each instance.

For persons enrolled in vocational rehabilitation programs, reassessment goes on at two different stages. During an extended evaluation period to determine vocational rehabilitation potential, the focus is on data that would support the decision to maintain eligibility. The IWRP developed following this evaluation period must include "a procedure and schedule for periodic review and evaluation of progress toward achiev-

ing rehabilitation objectives based on objective criteria and a record of those reviews and evaluations” [361 .41(a)(5)] (Federal Register, Jan. 19, 1981). The State plan for vocational rehabilitation services must also include “an evaluation of the effectiveness of the State’s vocational rehabilitation program in achieving service goals . . . as established in [its] plan” [361.17(c) 1 (Federal Register, Jan. 19, 1981)]. There is no specific provision for the use of data derived from the IWRPs as to the degree of accomplishment of objectives. There is merely a requirement that there be documentation of the existence of these data in case records.

The existing reporting system based on the evaluation standards issued in 1975 moves in its Standard No. 6 toward the assessment of client outcomes. It seeks “to insure that the clients rehabilitated retain the benefits obtained from the rehabilitation process.” To determine the degree to which this standard is met it is necessary to collect data on the percent of rehabilitated clients still employed at 1 year, 2 years, or 3 years after closure of the case; their earnings; and the percent of time unemployed (86). A more comprehensive information system has been designed by the Rehabilitation Services Administration (RSA) but is not yet in place. This projected system is described later in this chapter as providing the potential for assessment of the effectiveness of services provided.

In the education of disabled children, the IEP has as one component a reassessment, on at least an annual basis, to determine whether short-term instructional objectives are being achieved. However, failure to achieve the stated objectives is not necessarily tied to the services provided (84):

Each public agency must provide special education and related services to a handicapped child in accordance with an individualized education program. However . . . the Act does not require that any agency, teacher, or other person be held accountable if a child does not achieve the growth projected in the annual goals and objectives.

Unlike the vocational rehabilitation data collection system, there is provision of the collection of data derived from IEPs at a State level [sec. 121a232] (Federal Register, Aug. 23, 1977).

Most far-reaching is the commitment to evaluation of effectiveness of services for people with developmental disabilities. The portion of Public Law 95-602 dealing with such disabilities mandates an evaluation system and ties it directly to data derived from the habilitation plans. State plans are required, under this section of the law, to phase in such an evaluation system as a condition of receipt of Federal funds with implementation of each State’s system of October 2, 1982.

Program effectiveness is to be judged, with data from habilitation plans, on the results of services provided to clients. The primary measure is that of changes in developmental status from entry into service to completion. Functional assessment scales are to be used, employing tests meeting specified criteria of reliability and validity appropriate to the areas of concern. There is an opportunity, therefore, for service providers to choose their own measures that will take into account the variability of clients and the need to use different scales. Data are to be collected on the numbers of clients by level of developmental status at entry and at the end of the reporting period. Thus, the percentage of clients making progress (or regressing) can be calculated (145).

Still another measure projected by this system is the proportion of client objectives achieved to the number of planned objectives. An analysis of costs and effectiveness can then be done using data on the cost of the services provided. In both these measures, further breakdown of effects can be determined by data concerning age, sex, type of disability, and area of primary functional limitation (e.g., self help, communication). Particularity noteworthy is the opportunity in this evaluation system to report data from the States as to the comparable effectiveness of similar programs.

Determination of Client Participation

In addition to the three major objectives of the assessment and planning system, a fourth objective is the participation of individuals in planning for their own needs. The evaluation process leading to individualized plans for treatment has been expanded in principle from one carried out for disabled persons to one potentially carried out *with*

disabled persons, with their parents or guardians, or with both.

Each of the laws discussed in this chapter has stated a commitment toward such participation. This provision recognizes that the underlying goal of treatment is independent functioning on the part of disabled persons; the very process by which plans are made may be seen as contributing to such a goal. More directly relevant to the emphasis of this study, the appropriateness of the technology recommended, whether training or devices, may be expected to increase if the user(s) are participants in the planning decision.

In the area of vocational rehabilitation, client participation in IWRP development is one aspect of the case record to be monitored in State plans. The regulations implementing Public Law 95-602 describe such participation as follows (85):

The individualized written rehabilitation program must be developed jointly by the . . . staff member and the handicapped individual, or as appropriate, his or her parent, guardian or other representative . . . A copy of the written program [must be provided] and each handicapped individual [must be advised] of . . . procedures and requirements affecting the development and review of individualized written rehabilitation programs . . . The State must assure that the individualized written rehabilitation program will be reviewed . . . at least on an annual basis. Each handicapped individual . . . must be given an opportunity to review the program and, if necessary, jointly redevelop and agree to its terms.

Documentation within the record of the IWRP is to include "the views of the handicapped individual, or, as appropriate, his or her parent, guardian or other representative, concerning his or her goals and objectives and the vocational rehabilitation service being provided" (85).

In the case of developmental disabilities, the habilitation plan is similarly required to be developed jointly with the person and, where appropriate, such person's parents or guardian or other representative. Further, at the time of the at least annual review of such a plan, "in the course of review, such person . . . shall be given an oppor-

tunity to review such a plan and participate in its revision" (214). Documentation of such participation would presumably be included in the requirement for assurances from the States in their State plans that habilitation plans are being adequately implemented. However, there is no provision within the design specifications of the new comprehensive developmental disabilities evaluation system for direct incorporation of such data as parental participation. It is unlikely, therefore, that data on participation would be readily available for policy review on an easily accessible basis.

There are extensive provisions within the regulations implementing Public Law 94-142 for the disabled child's (parents') participation in the entire assessment and planning process. At present, however, there is no management information system that collects data on actual parental participation. Such data would ordinarily be collected in the course of sampling IEPs in field reviews.

Summary of the Effectiveness of the Assessment and Planning System

The collection of data from individualized program plans could be particularly crucial to planning for technological needs. However, the existing vocational rehabilitation information system does not incorporate data derived from IWRPs as to the services required. The projected developmental disabilities evaluation system does attempt to incorporate data on specific service requirements. There is no expectation that such information will be collected on the education of disabled children.

Measurements of the effectiveness of the services actually provided are also potentially available from the individualized program plans. Again, however, the existing vocational rehabilitation information system does not collect data directly from IWRPs. The projected developmental disabilities evaluation system does have that potential. Although existing regulations make provision for the collection of data on the education of disabled children, there is no plan for the direct collection of data as to effectiveness of services from IEP review.

Measurement of the degree of participation of disabled persons in the planning process is generally carried out as a component of administrative reviews but not part of any projected management information systems.

The next portion of this chapter examines the technical and other difficulties in the assessment and planning approaches being used in individual cases.

METHODOLOGICAL ISSUES IN ASSESSMENT AND PLANNING

This section, as the previous one, is organized by the three major objectives of the assessment and planning system: 1) determination of eligibility, 2) development of an individualized plan for rehabilitation (“determining need for services”), and 3) evaluation of the individualized plans’ ability to contribute to assessment of the effectiveness of services.

Technical and methodological issues arise with each of these objectives. Each of the program areas being surveyed—vocational rehabilitation, developmental disabilities, education of disabled children—share these issues. For purposes of the analysis in this section, however, the methods in use for the determination of eligibility will be explored in the area of education of disabled children; the development of functional plans will be explored primarily in the area of developmental disabilities; and evaluation of the effectiveness of services will be explored primarily in the area of vocational rehabilitation.

Determination of Eligibility

There is a distinction between the methods appropriate for the determination of eligibility and the methods that may be required for the generation of individualized plans. This distinction is tied to the identification of impairments, as required by each of the existing laws, versus the identification of actual functional disabilities that may result from such impairments. In the following discussions, it is important to remember that although the various laws use the term “handicapped” interchangeably with “disabled,” OTA reserves the term “handicapped” to mean the result of the interaction of a person with a disability and the environment, as set forth in chapter 2,

Several of the methodological issues concerning the determination of eligibility lie in the

medical framework from which many of the methods arose. In Nagi’s formulation (148), various etiologies (or causes) such as infection, trauma, or metabolic imbalances interrupt the normal processes of the body. The body responds to such interruptions by mobilizing its defensive and coping mechanisms in an attempt to restore a normal state of existence. These responses are then observed as a state of pathology. Modern scientific medicine is concerned with the relationship of pathological findings to underlying causes. Treatment in the medical framework is intended to help the organism regain equilibrium by providing medical or surgical intervention.

Medically, impairments are findings of loss or deviation from the “norm” which may be a result of active pathological processes but may also remain even after the underlying causes are no longer operative. For example, impairments such as congenital deformities may be thought to have occurred as a result of infection or some other harm prior to birth. These impairments are described in terms of the organs affected. Their prognosis, such as prospects for recovery and stabilization, is also described. The medical questions to be answered by the history and physical examination are: 1) the nature of the disorder or disease process; 2) the activity of the process (acute exacerbation, remission, or exhaustion of active disease); 3) the specific structure and site affected; 4) what medical treatment is appropriate and its possible complications.

Some of the data collected by the medical approach are relevant to the treatment of persons who also have disabilities, but it is important to recognize the limitations of this model of data collection, derived as it is from acute illness. For persistent conditions, the determination of impairment tends to place “undue emphasis on morphological diagnosis with . . . subordination of func-

tion to form, and . . . pathological phenomena are considered as though they are unrelated to the individual in whom they become manifest" (229). For the affected individual, it is not so much the underlying disorder and its resultant impairments that are of greatest concern but the manner in which they impinge on everyday life (87). Further, an impairment does not necessarily indicate that disease is present or that the individual should be regarded as sick. One basic methodological issue, therefore, is the use of experience and models based on acute illness to establish methods for the analysis of long-term problems.

Even less appropriate is the extension of this set of medical questions to intellectual and mental impairments in fields such as mental health or education. Except for certain organic diseases, there is an absence of any ability to differentiate indicators of pathology, impairment, and disability. The manifestations are behavioral. There is an absence of well-established criteria for classification relevant to decisions as to treatment. Different sets of criteria may result in differing reported patterns of disability (148).

Despite such incongruities, however, the same methods in use for the determination of disease are used in education. Diagnosticians in this field are concerned whether "disease" in the guise of developmental differences is present. Categories of "problems" have been established by tests based on "norms." For example, the diagnosis of "learning disabilities" has, at least historically, been established in large part by a child's scoring lower on the performance subtests and higher on the verbal portion of the widely used Wechsler test. Considerable effort is devoted to relating patterns of "deviance" to some causal event(s) in the life of the child. Thus, children with developmental problems are categorized as "brain injured," "emotionally disturbed," or "culturally deprived." Other categories in use are designated on the basis of some functional problem, presumed abnormality in some specific site in the nervous system, and presumed cause. Dyslexia, for example, is the diagnosis for a functional problem in reading associated with a presumed abnormality in the visual cortex of the brain and a strongly positive family history of similar difficulties.

One of the difficulties with this approach is that the criteria by which children are assigned to a specific category are elusive and ill defined. Such categorization is almost always arbitrary and subject to disagreement.

The present system of categorizing "deviant children" has come under recent attack as being culturally biased. Opponents maintain that the taken-for-granted value framework in which professionals operate (using tests based on the total population) limits the opportunities of children with minority backgrounds. The central issues here are both technical and, even more important, conceptual and ethical (142).

The problems of the existing classification system are summarized in the report of the Project on the Classification of Exceptional Children (109):

To call a child retarded, disturbed or delinquent reduces our attentiveness to changes in development. To say he is visually impaired makes us unappreciative of how well he can see and how he may be helped to see better . . . competent authorities agree that categories impede program planning for individual children by erecting artificial boundaries, obscuring individual differences, inhibiting decision-making by people closest to the problem, discouraging early return of children to the regular classroom, harming children directly by labeling and stigmatizing, and denying service to children with multiple handicaps and to other children who do not fall into neat categories.

The methods for determining the existence of impairments, and thus eligibility for services, in the various program areas are derived from a medical framework, which is often applied inappropriately. The methods often depend on categorizations that are frequently incorrect—and when presumed correct, are frequently harmful to the individuals involved.

The methodological limitations of the data actually collected using the medical framework-based process are even more germane to the issue of the appropriateness of services provided. To a considerable degree, a small number of standardized tests are given to determine a child's educational program. Keogh (120) pointed out the

potential inappropriateness of data derived from psychological testing. The normative (based on “norms”) framework provides quantification that may be excessively generalized, such as the intelligence quotient (I.Q.) used for placement for mentally retarded people. Qualitative data on the functional characteristics of persons (e.g., how they organize, the kinds of cues they select to guide their actions, their speed of decision, and their persistence) are not collected by the standardized measures currently in use, despite the documented relevance of such traits (38).

The methods in use to determine eligibility have been ineffective in providing useful data even for the purpose of appropriate placement of the child. The operation of Public Law 94-142 has, in addition, increased the use of these determinations of eligibility. That law has placed a premium on the identification of disabled children in order to receive Federal reimbursement for each child identified. Support has been given for finding larger numbers of disabled children despite considerable question as to the figures projected (99).

Under Public Law 94-142, the goal of parental involvement in the process of determining eligibility has led to the provision of due process hearings and a full system of legal recourse. The existence of legal remedies has been cited as one cause of what appears to be excessively comprehensive testing (99). Such testing may be done as a precautionary defense against possible legal action. Yet the data derived from standardized tests are frequently inadequate to deal with disputes as to eligibility. The actual tasks of a classroom are not sampled; data are not collected about the conditions under which the child functions most effectively. The methodological limitations of the procedures in use to determine eligibility may contribute to perhaps unnecessary litigation rather than to problem resolution.

In summary, the eligibility determination methods may be ineffective in aiding decisions about appropriate educational placement, particularly in the face of cultural diversity and the need for flexibility to create or use “least restrictive environments.” The methods are often inefficient, perhaps because they are burdened with substantial demands for evaluations of questionable util-

ity. They yield insufficient specificity on the characteristics of identified problems in a child. Rather than contributing to effective parental involvement, they frequently limit and obscure potential areas for collaboration between parents and schools.

Determination of Services Required

The development of individualized program plans is the second stage of the assessment process. These are relatively new requirements, and there is a less highly developed methodology to deal with the identification of problems in functional terms, the identification of the appropriate means by which problems may be solved, and ultimately the making of the plan to do so.

The focus in planning is shifting from the delineation of *impairments* inherent in the determination of eligibility to the delineation of *disabilities*. However, the distinction is sometimes difficult to apply, because the medical model so prevalent in the area is oriented to the identification of patient problems in terms of impairments. The “medically based” concept of *disability* is derived from the concept of loss of function or “deviation from the norm” used to establish the existence of disease in the first place. Thus, this merging of the concepts of impairment and disability permeates the methods for problem identification and for planning rehabilitation.

The notion of (re)habilitation used by the World Health Organization indicates some of the limitations of the standard concept. It has been defined as “the combined and coordinated use of medical, social, educational, and vocational measures for training and retraining the individual to the highest level of functional ability” (229). This specification puts little emphasis on the individual autonomy of the client in the rehabilitation process and concentrates on professional actions—doing something to and for somebody. Wood advocates a definition such as “restoration of patients to their fullest physical, mental and social capabilities, within the limits of a disability” (229). The inference is that the person has been placed at a disadvantage in failing to fulfill what has been expected of him or her because of the presence of illness or other disorder. Wood feels that it is

then possible to begin to formulate objectives such as maximizing performance and promoting expectations commensurate with altered capabilities. The ultimate goal, again according to Wood, is restoration of the patient's good name, which involves exploration of new roles that are acceptable both to the individual and to society (229).

A different approach has been advocated by some disabled persons and eloquently expressed by Finkelstein (88). He suggests that "disability" be viewed as a special class of social relations between persons with impairments and their social and physical environment. As chapter 2 indicates, OTA prefers this approach, but uses the term "handicap." The traditional analysis, inherent in the concepts expressed by Wood, has been that the person with impairments has failed to meet the socially imposed nondisabled standards of typical functioning. Finkelstein suggests that the focus should shift to the social context in which the problem exists. The example is given of the wheelchair user as being unable to get through the doorway. The focus is on the architectural barrier. It is an architectural problem and it can be studied, analyzed, and solved independently of the individual disabled person. Focus may then shift from the disabled person(s) to the environment, which may be modified.

The methodological issues in the making of an individualized program plan may be analyzed in light of this background. The step of problem identification is crucial to the making of an appropriate plan. To a considerable degree, the framework of expected behavior or "norms" has been retained from the medical approach, which focuses on the areas of loss. The assessment procedures identify areas of deviations from a "norm." To an even greater degree, the focus has been on the disabilities residing in the person, and not on those in the environment nor on the inappropriate interaction between person and environment.

The procedures in use with persons with developmental disabilities will be analyzed as an example.

The characteristics of developmentally disabled people, more specifically those who are defined as mentally retarded, require considerable preci-

sion in designing rehabilitation programs. Progress may be expected to be slow, but it may be enhanced to the degree that training program objectives are clearly defined. Assessment instruments (tests) leading to a more precise identification of functional problems have therefore proliferated (75). These behavioral rating scales are used for prescriptive purposes rather than the diagnostic purposes of the general intelligence tests. They are applied directly to the design of individualized program plans and are thus useful at the time of re-test as a measure of progress in meeting objectives. If used on a wide scale, they may also be used for overall program evaluation.

At their best, these behavioral scales describe the levels of function an individual has reached and is able to reach rather than simply what the individual is unable to do. They also describe the criteria to be met rather than attempting to relate those criteria to standardized "norms." The selection of the particular functional content areas to be sampled, still reflect the cultural bias of the test developers.

Far less highly developed are rating scales which sample the environment in which the individual is required to function. An individual's developmental progress may also come about by changes in the environment. Many of the existing "environmental" assessment laws require a focus on the "least restrictive environment" (75). As such, categories examined in environmental assessment tend to include such things as the degree of autonomy permitted and the exercise of individual rights, as well as the amount of activity available in programs. Particularly noteworthy is the Community Adjustment Scale, which directly samples both the individual's ability to perform tasks and the opportunities afforded by various sites available to the individual to perform those skills (75).

Despite the wide range of rating scales available, many important areas of function are apparently not ordinarily surveyed in relation to developmentally disabled people. These include functions related to work habits and work adjustment, as well as emotional development.

All the instruments surveyed are concerned with the measurement of status. That is, data are collected concerning what the person is able or

unable to do. Data are not collected concerning the conditions under which the person has been able to accomplish whatever has been accomplished. Data are not collected regarding the process by which development has come about and might come about in the future. The failure to collect such data is inherent to the testing model that underlies assessment.

Nevertheless, data on *process* could be very useful to the making of an individual program plan, where it is necessary to identify not only problems and possible objectives but also the most appropriate means by which the objectives might be met.

The traditional commitment to the collection of replicable quantitative data has generally limited data to that collected by professionals and not usually from those people most directly and frequently involved with the disabled person. The search has been for objective data uncontaminated by interaction between the person with disabilities and the examiner. This goal has limited the value placed on data derived from more natural settings and has limited the participation of parents and disabled persons themselves in the assessment process (75).

A recent, large-scale study, focusing on a range of disabilities including developmental disabilities, described the degree to which individualized planning procedures have been implemented in education (188). In a survey of 208 school districts in 46 States, the study reviewed the individualized plans of about 2,500 students receiving special education and related services in public schools and an additional 550 students in special facilities. Parents were found to have provided inputs to the planning process in about one-half, and students in about 10 percent of the cases (188). Only 20 percent of the parents were thoroughly familiar with the contents of the plan. Although there was awareness of the child's placement and the general services being provided, parents were less familiar with the goals and the short term objectives (188).

This low level of parental awareness of the objectives of the plans made for their own children suggests that there may be considerable limits on the degree to which parents can effectively par-

ticipate in the *implementation* of the plans. A major resource in terms of parental support and cooperation may therefore be lost. Such cooperation is particularly crucial in the treatment of children who are severely disabled.

The survey indicates that a more generic problem may exist in the entire planning process. The relationship between identified problems and the goals and objectives set was not well documented. Such relationships were documented in respect to language programs in a majority of cases. However, many of the plans did not have goal statements and objectives specified for identified needs. Plans concerned with speech and mathematics were complete in about one-half the cases. Areas such as social adaptation, self-help skills, motor skills, and vocational/prevocational skills, where parental input and participation in implementation of programs might be most helpful, were complete in less than 25 percent of the cases (188). Although almost all plans surveyed contained information as to the services to be provided, the lack of connection made between the service objectives and identified need brings into question the effectiveness of the entire planning process in determining appropriate services.

Determination of the Effectiveness of Services Provided

The review of individualized program plans at specified intervals is the third stage of the assessment process. In each of the areas being examined in this chapter—vocational rehabilitation, developmental disabilities, and education—there is a provision that, after the plan is made, the degree of accomplishment of the objectives originally set must be evaluated and the plan accordingly revised for the next interim. The principle of a cyclical procedure in which evaluation of the effectiveness of services is an integral part of the rehabilitation process has thus been established. The provision for client involvement in the planning stage also extends to this evaluation stage. This review and revision is a relatively new requirement for human service programs, and both technical and conceptual issues arise in its implementation.

The vocational rehabilitation program will be used as an example for the purposes of this analysis.

Measurement of client outcome in terms of "case closure" by the attainment of employment has been well established in vocational rehabilitation. The largely public source of funds for vocational rehabilitation has mandated a commitment to accountability and statistical reports (86). The use of outcome data from the IWRP is a more recent phenomenon. A management information system incorporating data from the IWRP is being developed (as of early 1982). The need for the collection of data on a large scale for the evaluation of rehabilitation programs and rehabilitation counselors has been one of the major incentives behind the development of methods in this area. However, the focus for discussion in this analysis will be on the implications of evaluation methods in respect to services provided for the individual client.

Many of the methodological issues described earlier concerning the identification of problem areas and objectives for rehabilitation are also directly applicable to the evaluation stage. Rating scales descriptive of functional behaviors are used as a posttest to measure changes in the client. These rating scales must also meet the need for a system of relatively specific indicators that reflect the wide range of possible settings for rehabilitation and the possible sequence of outcomes within any one setting. They must permit agreement between observers as to outcome achieved. The measurement of outcomes must also address the issues inherent in the collection of data in standardized test settings versus more naturalistic ones and in the collection of data by professionals versus those who are more directly consumers of services. Just as in the determination of the initial plan, there must be awareness of the process by which data are collected and the source of such data (114).

Recent changes in the vocational rehabilitation programs have mandated a commitment to dealing with "more severely disabled" people, and outcomes to be sought now include not only the ability to function within the work force but also to live more independently. The "independent living" provisions of the Rehabilitation Act mark a

fundamental change in the character of the goals of rehabilitation. A significantly different approach is required, because the principle of independent living does not necessarily imply that one is free of the need for services, but rather that those services are under the control of the disabled person (45).

An expanded management information system for vocational rehabilitation has been in the process of development over the past several years (7,45). Within the past year, the character of this projected system has been extensively modified to incorporate scales measuring functional aspects of clients. It is also planned that the system will use life status indicators for measures of IWRP goals and client changes. Plans to test this new system, which was developed in close collaboration between RSA and State vocational rehabilitation agencies, are now underway. This section will focus on this developing system as the expression of present thinking on evaluation.

The movement away from the identification of client problems in medical or psychiatric diagnostic categories of impairment has been well established in vocational rehabilitation. A number of functional assessment measures have been developed, and two have gained particular acceptance—the "functional assessment inventory" (FAI) developed by a group at the University of Minnesota (43) and "rehabilitation indicators" (RI) developed by a group at the Rehabilitation Institute at New York University (71,72). The goal of both these measures has been to provide behavioral statements that are readily observable and reliably measured by different observers. Both measures, but particularly the RI, can be used to provide descriptors of a range of goals and problems to be corrected and may then be used in the evaluation of client changes. The focus in the FAI is mainly on the characteristics of the client, rather than the environment. Out of the 30 categories of problems, only two have their locus outside the individual. A new scale, not yet being used, will describe "elements of the person's physical, social, cultural, and political environment that may hinder or support goal attainment" (72).

The availability of these functional assessment measures has led to the incorporation of items

from both in the projected management information system for vocational rehabilitation on a national basis. “Life Status Indicators” from the RI scale are to be used to reflect client characteristics at entry into the rehabilitation process and at the completion of the service to assess change. For example, one such status indicator relates to self-care: a four-item scale ranges from “needs substantial assistance” through “occasional assistance” and “minimal assistance” to “needs no assistance.”

Other measures of effectiveness of service relate to the more traditional aspects of rehabilitation, focusing on ability of clients to function in the work force. These include increased economic independence in terms of employment at or above the minimum wage, removal from public assistance rolls, and percentage competitively employed.

The potential use of the IWRP as the primary planning mechanism is recognized only to a limited degree. Measures that would evaluate the contribution of the services actually provided in accordance with the IWRP to any of the outcomes are apparently not contemplated. Moreover, there is no measure of the degree to which the client has taken active part in the planning and evaluation process mandated by IWRP procedures.

The evaluation system for vocational rehabilitation has addressed the implications of the independent living movement only in part. There has been attention given to measures other than traditional ones related to employment, in recognition of the movement toward working with people with more severe disabilities. However, there have not been substantial changes in how rehabilitation problems are viewed: The problems are not yet widely seen as centered in the environment as well as in the disabled person. Even *more* crucial to the independent living movement has

been the issue of the rehabilitation process itself and active client involvement in decisionmaking. This has not been addressed directly either in the functional assessment scales or any of the other data collection sources.

There is a critical need at this stage of the process for data not only on status but also as to the *means* by which successful outcomes were achieved:

Evaluation has traditionally been perceived as an end point activity. The principle of assessment-planning-evaluation incorporated in the IWRP process could more effectively be considered as an ongoing, cyclical process. Plans should be revised in light of experience.

Evaluation has been traditionally perceived as dealing with the measurement of outcomes alone. The potential clearly exists, although rarely realized, to collect data as to what means were most useful in bringing about whatever successful outcomes occurred.

Evaluation has traditionally been perceived as separate from treatment. However, the assessment-planning-evaluation process may in itself be a major and ongoing therapeutic activity, especially if focused on the means by which problems have been solved.

If a major goal of rehabilitation is to encourage the development of disabled persons to take control of their own lives, one *skill* to be engendered and fostered is the ability of disabled persons to plan for themselves. Thus, the abilities of disabled persons to answer pertinent questions for themselves—about successes and the strategies for achieving them, about problems to be encountered, and about goals and the means for realizing them—should be exploited and enhanced (172).

TECHNICAL ADDENDUM TO CHAPTER 3

Individualized Written Rehabilitation Program (Public Law 95-602)

[An] individualized written rehabilitation program . . . in the case of each handicapped indi-

vidual is developed jointly by the vocational rehabilitation counselor . . . and the handicapped individual (or in appropriate cases his parents or guardians) . . . Such written program shall set forth the terms and conditions, as well

as the rights and remedies, under which goods and services will be provided to the individual . . . Such program shall include . . . (1) a statement of long-range rehabilitation goals for the individual and intermediate rehabilitation objectives related to the attainment of such goals, (2) a statement of the specific vocational rehabilitation services to be provided, (3) the projected data for the initiation and the anticipated duration of each such service, (4) objective criteria and an evaluation procedure and schedule for determining whether such objectives and goals are being achieved . . . [Public Law 95-602: sec. 7(5), sec. 102(a)].

Individualized Habilitation Plan or Habilitation Plan (Public Law 95-602)

(1) The plan shall be in writing.

(2) The plan shall be developed jointly by (A) a representative or representatives of the program primarily responsible for delivering or established, (B) such person, and, (C) where appropriate, such person's parents or guardian or other representative.

(3) The plan shall contain a statement of long-term habilitation goals for the person and the intermediate habilitation objectives relating to the attainment of such goals. Such objectives shall be stated specifically and in sequence and of progress. The plan shall (A) describe how the objectives will be achieved and the barriers that might interfere with the achievement of them, (B) state objective criteria and an evaluation program and schedule for determining whether such objectives and goals are being achieved . . .

(4) The plan shall contain a statement (in readily understandable form) of specific habilitation services to be provided, shall identify such agency which will deliver such services, shall describe the personnel (and their qualifications) necessary for the provision of such services, and shall specify the date of the initiation of each service to be provided and the anticipated duration of each such service . . . (C) Each habilitation plan shall be reviewed at least annually . . . In the course of the review, each person and the person's parent or guardian or other representative shall be given an opportunity to review such plan and to participate in its revision . . . [Public Law 95-602: sec. 112(b)].

Individualized Educational Program (Public Law 94-142)

The individualized educational program for each child must include: (a) A statement of the child's present levels of educational performance (b) A statement of annual goals, including short term instructional objectives; (c) A statement of the specific special education and related services to be provided to the child, and the extent to which the child will be able to participate in regular educational programs; (d) The projected dates for initiation of services and the anticipated duration of the services; and (e) Appropriate objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether the short term instructional objectives are being achieved . . . [sec. 121a.346 of the regulations implementing Public Law 94-142] .