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# 9

## **Delivery, Use, and Financing of Technologies**

The first of earthly blessings, independence.

—*Edward Gibbon*

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# Delivery, Use, and Financing of Technologies

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## INTRODUCTION

The desired result of research, development, evaluation, and diffusion of technologies is the use of these technologies by disabled individuals. In order to develop a framework for examining the fit between the individual disabled person's needs, desires, and capabilities and specific technologies, it is necessary to assess the current system of use of technologies. This system includes selecting technologies, providing technologies, and paying for them. Assessment of this system also relates directly to issues of resource allocation.

The use of technologies by disabled people appears to depend primarily, but certainly not entirely, on the public and nonpublic programs and services for which the individual users are eligible. Through their affiliation with these programs and services, users either receive technologies directly, have them financed, or learn about them. "Public programs" are those provided by the governmental sector, whether at the Federal, State, or local level. "Nonpublic programs" are those provided by all other sectors of society. The nonpublic (or "private") sector may be further divided into the "for-profit" sector (which would include manufacturers and commercial insurance companies) and the "not-for-profit" sector (which would include foundations, voluntary health agencies, universities, and professional associations).

One reason the use of technologies is dependent on eligibility for programs is that many disabled persons are poor. Three-fifths of disabled adults of working age earn incomes at or near the poverty level (17). In 1977, the median family in-

come (including public assistance) for severely disabled individuals was slightly over half that of the nondisabled (70). These figures must be kept in perspective, however, because they may be excluding the many disabled people who have higher incomes and are thus not in programs from which much of the data is drawn.

Furthermore, of 15 million disabled Americans between ages 16 and 64, more than 7.7 million are either out of the labor force by choice or unemployed (17).

A second reason the use of technologies is dependent on eligibility for programs is that information on available technologies reaches potential users primarily through the variety of programs that exist. One type of program provides the technologies directly, with the professionals on staff either disseminating information on possible choices or prescribing professionally selected technologies, training the client in their uses, and monitoring their effectiveness. Another type of program serves as an information source for eligible clients.

This chapter describes the significant public and nonpublic programs that affect the use of technologies by disabled people. Programs legislated and funded by the Federal Government are emphasized. Because this chapter covers a range of programs, issues pertaining to particular programs are discussed following the relevant program description. Issues pertaining to the service delivery system as a whole are then discussed separately.

## CURRENT ACTIVITIES AND PROGRAMS

### Public Programs

There are many public programs that serve disabled individuals at the Federal, State, and local levels. These programs vary in their purpose, origin, definitions of disability, and criteria for eligibility. Some serve specific disability groups, others serve all disabled people who meet non-diagnosis-specific eligibility criteria, while others serve disabled persons through funds earmarked from broader programs. Programs also differ in their methods of providing services (which include alternatives such as funding only, funding plus referral to services, or direct service provision), in their financing, and in their administration.

In 1975, the Office of Handicapped Individuals of the Department of Health, Education, and Welfare (DHEW) surveyed all Federal programs that serve disabled people, and it found 75 programs that focused on serving disabled people, 6 programs that were not exclusively for disabled people but emphasized serving them, and 45 programs that mandated serving disabled persons but on the same basis as able-bodied people (83). A more recent survey (1981) found 83 programs targeted to disabled persons and 50 that include these individuals as beneficiaries (122). Thus, in recent years, the number and diversity of Federal programs serving disabled people has remained fairly constant. These programs are administered by 22 Federal agencies and are concerned with nearly every aspect of a disabled individual's life. It should be noted that authority for more than one program may stem from a piece of legislation.

Although there are over 100 different Federal programs serving disabled people, the majority of public services are in the form of: 1) income maintenance, 2) health and medical care, 3) social services, 4) educational services, and 5) vocational rehabilitation and independent living. Other services, not discussed in depth in this report, include special housing programs and transportation systems. Clearly, the greatest expenditures for disabled people have been and continue to be made for income maintenance and related transfer payments and health and medical care (8,83,122,130, 208). For most programs, the majority of dollars

come from the Federal Government; Federal funds are often supplemented by mandatory or optional State or local matching funds. The Urban Institute estimated that in 1973, \$15.3 billion in public funds was spent on income maintenance and related transfer payments, \$7.9 billion was spent on health and medical payments, and \$1.1 billion was spent on other direct service payments (including education and social services) (208). In 1977, these figures increased to \$29.8 billion for income maintenance and transfer payments, \$7.7 billion for health and medical payments, \* and \$2.4 billion for direct services (8). Thus, similar proportions of total funds were spent in each area. In the case of funds spent on children only, the greatest amount is spent on special education, followed by lesser amounts for transfer payments and medical care (118). A summary of Federal expenditures for disabled people under the programs discussed in this chapter is presented in table 8.

### Income Maintenance

The major income maintenance programs for persons with disabilities are the Social Security Disability Insurance (SSDI) program, the Supplemental Security Income (SSI) program, Veterans Administration (VA) compensation for service-connected disabilities, and VA pensions for nonservice connected disabilities.\*\* In fiscal year 1980, Federal expenditures for disabled recipients were \$15.0 billion under SSDI and \$3.9 billion under SSI. ' \* \* There were 4.8 million SSDI and 2.3 million SSI beneficiaries (130). For the VA programs, \$6.1 billion was spent for 2.3 million vet-

\*Different authors categorize expenditures in different ways, depending on their assumptions and definitions. Thus, it is difficult to compare figures from source to source, although they may be useful in examining the magnitude or direction of the spending. In this case, it is unlikely that medical payments due to disabling conditions decreased from 1973 to 1977, but rather, it is certain that some programs included in the 1973 figure were not in the 1977 figure. It should also be noted that the latest year for which figures are available varies from program to program.

\*● State-run worker's compensation programs are an additional source of aid to handicapped people. Since these programs are outside of the Federal Government, they will not be discussed in depth. They operate in all States to provide benefits for work-related impairments or death in the form of cash assistance and/or medical care (130). In 1977, \$5.1 billion was spent for income maintenance payments and \$2.5 billion was spent for medical care (8).

● \*\*These figures exclude administrative expenses.

Table 8.—Federal Expenditures for Disabled People Under Selected Programs<sup>a</sup>

Program	Amount of expenditures <sup>b</sup> (000s)	Number of beneficiaries (000s)
<b>Income maintenance</b>		
SSDI . . . . .	\$15,000,000 (FY 80)	4,800
SSI . . . . .	\$3,900,000 (FY 80)	2,300
Veterans Administration		
Compensation . . . . .	\$6,100,000 (FY 80)	2,300
Pensions . . . . .	\$800,000 (FY 80)	900
<b>Health and medical care</b>		
Medicare		
Related to disabling conditions . . . . .	\$1,400,000 (1977)	3,300 (FY 80)
Total benefits for disabled people . . . . .	\$4,000,000 (FY 80)	
Medicaid		
Related to disabling conditions . . . . .	\$2,800,000 (1977)	3,300 (FY 80)
Total benefits for disabled people . . . . .	\$3,500,000 (FY 80)	
Veterans Administration		
Related to disabling conditions . . . . .	\$816,000 (1977)	600 to 1,300 (FY 80)
Total benefits for disabled people . . . . .	\$3,000,000 to \$5,600,000 (FY 80)	
<b>Other programs</b>		
Developmental Disabilities . . . . .	\$62,400 (FY 80)	3,600 <sup>c</sup>
Title XX . . . . .	\$841,000 (1977) <sup>d</sup>	Not available
Education for all Handicapped Children . . . . .	\$951,000 (FY 79)	3,900
Vocational Education . . . . .	\$55,000 (FY 79)	2,100
Title 1, Elementary and Secondary Education Act . . . . .	\$143,000 (FY 80) <sup>e</sup>	222
Handicapped Children's Early Education Act . . . . .	\$20,000 (FY 80) <sup>f</sup>	Not available
Vocational Rehabilitation . . . . .	\$1,400,000 (FY 80)	1,100

NOTE Numbers from refs 8, 58 122 128, 129 132, 215

<sup>a</sup>These programs include those discussed in ch 9 Other programs for disabled people, such as those under the Department of Labor Department of Transport at ion and Small Business Administration, for example are not included Generally expenditures under omitted programs are significantly lower than those presented<sup>b</sup>Many of the dollar and beneficiary figures are estimates rather than actual counts They are also from different years and sources and should be used to compare magnitudes rather than added to obtain total counts Unless otherwise noted the year of the beneficiary count is the same as the year for the money spent<sup>c</sup>This figure represents the DD population not the number of beneficiaries Some disabled people who do not meet the criteria to be classified as developmentally disabled receive services from DD agencies.(184)<sup>d</sup>This figure includes State funds<sup>e</sup>These figures represent appropriations rather than expenditures

SOURCE Office of Technology Assessment

erans under the compensation for service-connected disabilities program (122,215), and \$0.8 million was spent for 0.9 million beneficiaries under the pensions for nonservice-connected disabilities program (130). As will be noted below, these programs are important for recipients not only for the income they provide but also for supplemental benefits and referrals to other services. Both physical and service technologies are provided under the supplemental benefits. The income itself allows the recipients to purchase technologies not covered by the supplemental benefits.

SSDI is a Federal social insurance program for workers who have contributed to the social security retirement program and become disabled before retirement age. In order to become eligible for benefits, a worker must have 20 quarters of coverage in the 40 quarters prior to the onset of disability and must meet the statutory test of disability or blindness. Under the statutory test for disability, the individual must be unable to engage in any substantial gainful activity (SGA) due to a medically determinable physical or mental impairment expected to last at least 12 months

or result in death (58). If a blind individual meets the statutory test for blindness, he or she may be declared eligible for benefits if unable to engage in SGA comparable to previous gainful activity in which engaged (213). Once application is made, there is a 5-month waiting period for receipt of benefits. Disabled spouses and dependent children may receive benefits upon the retirement, disability or death of the primary beneficiary.

Individual SSDI beneficiaries receive cash payments with no restrictions on their use. These payments are distributed by the Federal Government (although eligibility determinations are made by State vocational rehabilitation agencies) from the Disability Insurance Trust Fund, which is financed by a payroll tax. In addition to cash payments, beneficiaries receive two other benefits—health insurance coverage under title XVIII of the Social Security Act (Medicare) and referral to, and thus use of, vocational rehabilitation services. Medicare coverage begins after 24 months of SSDI payments; funds are transferred from the Disability Insurance Trust Fund to State vocational rehabilitation agencies. Federal dollars cover 100 percent of the cost of vocational rehabilitation services for eligible SSDI recipients. In fiscal year 1979, \$102 million was expended (138).

The SSI program is a Federal cash assistance program whose purpose is to guarantee needy aged, blind, and disabled individuals a minimum income. Although the statutory definition of disability is the same as that under the SSDI program, SSI exhibits an important difference from SSDI, because eligibility for SSI is based on the individual's current status without regard to previous work or contributions to a trust fund (83). In order to qualify for benefits, an applicant must first fulfill the definition of disability, then pass an income needs test (which, in reality, is included in the determination of disability), and must not have personal resources which exceed statutory limits. Certain children under 18 are eligible for benefits, but there is no provision relating to the eligibility of widows or widowers.

The SSI program originated from several State programs for disabled, aged, and blind persons. In 1972, the Federal program was enacted; it is administered by the Social Security Administra-

tion and funded out of general revenues. States may supplement the Federal program by adding to the Federal cash benefits or by broadening eligibility limits. This supplemental program may be administered federally at each State's request, in which case the administrative costs are borne by the Federal Government. If States select this option (27 have), they must agree to provide supplements for all SSI recipients of the same class (127).

Like SSDI beneficiaries, SSI beneficiaries receive unrestricted cash payments. They also receive numerous welfare-related services, including health insurance coverage under title XIX of the Social Security Act (Medicaid), social services under title XX of the act, and food stamps. Certain beneficiaries may receive vocational rehabilitation services. Finally, beneficiaries who require care in personal care homes or domiciliary care facilities may have their Federal SSI or State supplemental payments made directly to their institutions (66). \*

Clearly, the method of determining eligibility for the SSDI and SSI programs greatly affects the number and severity of beneficiaries and disabilities and thus, use of technologies. As noted earlier, the statutory definition of disability is the same for both programs, although the basis for each program is different (one is an insurance program and one is a welfare program). By law, the definition is meant to be a strict one so that only the most severely disabled individuals can meet it (213). It is the regulations rather than the statute, however, which specify how the definition is to be applied in individual cases. The State vocational rehabilitation agencies make the initial determination of disability based on medical considerations alone or on medical and vocational factors.

First, the agency makes a determination of whether or not an individual is engaging in SGA. Earnings below \$190 per month are considered not to be SGA, while earnings above \$300 per month automatically cause a finding of no disability.

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\* These institutions provide a lower level of skilled care than intermediate care facilities and as such are not covered under Medicare or Medicaid. Generally, room and board as well as some supervision in activities of daily living are provided.

Earnings between the two amounts must be evaluated further. If the individual is not engaging in SGA, a determination of whether or not the individual has a severe impairment—one which limits his or her physical or mental capacity to perform basic work-related functions—must be made. Past relevant work is not considered at this step. If a severe impairment is found, it is checked for inclusion on the Social Security medical listings for comparability and duration. At this stage, as long as the impairment is included in the listings or determined to have a medical equivalent in the listings, a finding of disability is made. In cases where the SGA and medical tests do not point to a clear finding of “disability” or “no disability,” vocational factors, such as ability to do past work or adjust to different work, are considered.

According to the Subcommittee on Social Security of the U.S. House of Representatives, there is good reason to believe that the process of disability determination is not uniform across the country. Furthermore, there is disparity between two levels of eligibility determination—the initial application at the State agency level and the appeal (permitted if a denial is made at the initial application) at the administrative law judge level. State agencies are denying benefits to 67.4 percent of initial applicants, yet administrative law judges are reversing these decisions at a 60-percent rate. The subcommittee also noted that Federal supervision and knowledge of the program have been weakened by a number of executive branch reorganizations since 1975 (212). A recent General Accounting Office (GAO) study (95) found a problem with removing individuals who are no longer disabled from the SSDI rolls. GAO estimated that as many as 584,000 beneficiaries who do not currently meet the eligibility criteria may be receiving benefits.

At the heart of the definition of disability under SSDI and SSI is the determination of an individual's ability to engage in SGA. Under SSDI, although there is no “means test” to determine eligibility, benefits are terminated if a recipient earns more than \$300 of counted income per month. Under SSI, since the program is designed to guarantee a minimum income, there is a reduction in benefits for dollars earned. It has been

noted that SGA is less than the poverty level and thus provides a significant disincentive for beneficiaries to work (17,83). Furthermore, the potential loss of supplemental benefits when SGA is declared, particularly the health insurance benefits under Medicare or Medicaid, provides an additional disincentive to work (17'),

Elimination of disincentives to leave the disability rolls and return to work has been widely discussed in the literature (12,17,68,83,104,130,138,146,156,213). One suggestion has been to raise the level of SGA (which has been done periodically since the SSDI program was enacted). In theory, a higher SGA level would mean that once a beneficiary was terminated from the SSDI or SSI roll, because of performance of SGA, his or her earnings would automatically allow financial self-sufficiency. Yet a special study by DHEW of the increases in the SGA level in 1966, 1968, and 1974 found that these increases were not accompanied by increases in beneficiary earnings (213). One apparent reason for this finding is that most disabled beneficiaries' earnings are substantially below the SGA level, and raising that level does not increase those earnings. Another suggestion has been to increase the wage-to-benefit ratio. This ratio can be increased by lowering benefits or by improving wages by liberalizing the provisions of the trial work period (to be discussed below), by improving the performance of rehabilitation counselors, and by making the labor market more receptive to the rehabilitated disabled population (104). Improving wages appears to be the preferable method—first, it is more equitable, and second, high benefit levels are not always the result of SSI or SSDI benefits. A study of SSDI beneficiaries showed that in 1971, 44 percent of those receiving SSDI benefits for 1 year or longer also received cash benefits from at least one other source. Furthermore, the average total benefits paid to those receiving multiple benefits were double the amount paid to those receiving only SSDI (146).

The Social Security Disability Amendments of 1980 (Public Law 96-265) attempted to strengthen work incentives in several ways (68,130). Many of the law's provisions affect both SSDI and SSI, although some apply only to one program. One provision is that extraordinary work expenses due to disability—such as those for attendant care

services, medical devices, equipment prostheses, and similar items and services—will be excluded from the calculations of whether the individual is engaging in SGA. A second provision is that a person's status as a disabled individual will be extended for 15 months after he or she has successfully completed a 9-month trial work period. Although the individual cannot receive cash benefits for more than 3 months of the extended benefit period, active benefit status can be reinstated if the work activity fails or the SGA level of earnings is not maintained. Prior to Public Law 96-265, there was a trial work period of 9 months after which the beneficiary's case was closed; new application and waiting periods were subsequently applicable.

A third important set of provisions in Public Law 96-265 relates to health insurance benefits. Indeed, potential loss of these benefits has been noted as one of the strongest disincentives to return to work. Their value alone is often more than the disabled recipient is able to purchase through his or her earnings, since the average cost of medical care is three times more for disabled persons than for able-bodied persons (17). Public Law 96-265 extends Medicare coverage for SSDI beneficiaries for 24 months beyond the automatic reentitlement period as long as there has been no medical recovery from disability. Furthermore, it eliminates the 24-month waiting period for Medicare for persons previously receiving SSDI who become eligible a second time. For SSI recipients, a 3-year demonstration program was authorized. Under this program, people who have completed the trial work period and continue to earn SGA receive a special benefit status that entitles them to retain Medicaid and social services benefits and in some cases, special cash payments. On a case-by-case basis, the Secretary of the Department of Health and Human Services (DHHS) is authorized to determine that former SSI recipients require Medicaid and/or social services to maintain employment or to provide for themselves a reasonable equivalent of SSI benefits. It is too early to assess the effects of these amendments on abolishing disincentives to work. A full report by the Secretary of DHHS to Congress on the effects of these amendments and on the programs in general is due by January 1, 1985.

As mentioned above, certain SSDI beneficiaries may receive vocational rehabilitation services under the Beneficiary Rehabilitation Program (BRP), and certain SSI beneficiaries receive such services under the SSI-Vocational Rehabilitation (SSI-VR) program. Under both programs, the services are provided by State vocational rehabilitation agencies and funded totally by the Federal Government (as opposed to the general Vocational Rehabilitation program under which States must contribute 20 percent). The primary purpose of funding the two programs is to save trust fund and general revenue dollars as a result of rehabilitating individuals into productive activity. Thus, the following criteria were developed for selecting beneficiaries to receive services (213): 1) the disabling physical or mental impairment is not expected to progress so rapidly as to outrun the effect of the vocational rehabilitation services or preclude restoration of the individual to activity; 2) without the services, the disability is such that the individual is expected to continue needing SSI or SSDI payments; 3) a reasonable expectation exists that provision of the services will restore the person to gainful activity; and 4) the predicted period of work is long enough that the benefits saved and future contributions to the trust fund are greater than the cost of the services provided. These criteria imply that only the least severely disabled beneficiaries in the SSDI or SSI program, who by definition must be severely disabled, are eligible for the BRP or SSI-VR programs. Indeed, in fiscal year 1979, there were only 94,936 beneficiaries in the BRP (138) out of a total 4.77 million beneficiaries on SSDI (69).

At issue currently is whether the Federal Government should continue to support vocational rehabilitation services as part of the income maintenance programs (96,129). One question is whether the programs are cost effective—i. e., whether the costs of services provided are less than the savings of cash benefits plus the contributions to the trust fund. A study of savings to the trust fund using vocational rehabilitation case data and SSDI benefit histories found the savings to be between \$1.39 and \$2.72 per \$1.00 of cost for SSDI beneficiaries who completed their vocational rehabilitation service period in fiscal year 1975 (138). The same study found that the cost of voca-

tional rehabilitation services would be fully repaid in 10 years. However, it also found that the loss of savings due to individuals returning to the SSDI rolls is substantially greater than the increased payroll tax revenue received during post-vocational rehabilitation employment. In contrast to the generally positive findings of the study of the BRP, a GAO study of the SSI-VR Program (96) found that the Federal funds spent greatly exceeded reductions in SSI payments. Furthermore, in 55 percent of cases studied, there were no reductions in SSI payments that could be attributed to a beneficiary's increased earnings. Similarly, a study of disability benefits and rehabilitation services found that persons who receive SSI benefits, SSDI benefits, or both, are rehabilitated (gainfully employed and removed from the benefit rolls) less frequently than nonbeneficiaries receiving the same vocational rehabilitation services, including other severely disabled vocational rehabilitation clients (12). The authors of that study note, however, that many SSI or SSDI beneficiaries who complete the vocational rehabilitation program remain on the benefit rolls, because the severity of their disability may prevent employment in the competitive market or because the disability benefits reduce their incentives to work.

A second question is whether the current recipients of vocational rehabilitation services under either the BRP or SSI-VR programs would be able to receive such services under the general vocational rehabilitation program. The general vocational rehabilitation program is now mandated to focus on severely disabled persons, which would include SSDI and SSI recipients. In addition, criteria for selection under the general vocational rehabilitation program are not as stringent, since it includes independent living as a goal (and not only gainful employment). However, the rehabilitation costs for income maintenance beneficiaries are roughly twice that for nonbeneficiaries. Thus, if scarce funds are not earmarked for those currently in the BRP and SSI-VR programs, there is less chance for those individuals to be selected for services (129).

The income maintenance programs for disabled veterans are completely separate from the civilian programs and have completely different bases for determining recipients' eligibility than the SSDI

or SSI programs have. Both the compensation for service-connected disabilities and pensions for nonservice-connected disabilities programs are administered by the VA and funded out of general revenues. There are no State or local supplements for either program. Similarly, there is no participation by State or local agencies in determination of eligibility.

Compensation for service-connected disabilities is a program whose purpose is to provide economic relief to veterans whose earning capacity is impaired due to their military service. The amount of compensation depends on the degree of disability which the impairment causes in earning capacity in a civilian occupation. Additional compensation is provided for dependents. To become eligible, a veteran first must have contracted a disease, suffered a nonmisconduct injury, or aggravated an existing disease or injury in the line of duty during active war or peacetime service. Proof of disability is based on the service medical records. Service connection may be granted by presumption if a veteran develops one of the specified chronic diseases within 1 year of discharge from service, tuberculosis or Hansen's disease with 3 years, or multiple sclerosis within 7 years. Once service connection has been established, the percentage of disability is assigned by VA from an established "Schedule for Rating Disabilities." Percentage range from 10 to 100 (215). Thus, the establishment of eligibility is based entirely on medical criteria (in addition to proof of service). No vocational factors are considered in individual cases. (Vocational factors were considered only when the "Schedule for Rating Disabilities" was developed.) Furthermore, the individual veteran does not have to show a lack of ability to earn an income or an inability to support himself or herself with unearned income.

Pensions for nonservice-connected disabilities is a program to provide an income to totally and permanently disabled veterans and their dependents whose income is below an established standard. To become eligible, veterans must have served at least 90 days including 1 day of war-time service, must meet a medical determination of disability, and must have personal resources and income below a legislated amount. At age 65, veterans are deemed to be disabled regardless of

their physical condition. Disabled survivors of veterans may also receive benefits if the income test is met (127). As noted earlier, this income-tested program is smaller than the nonincome-tested one. Eligible veterans receive cash payments (the amount is determined by statute), medical and social services under the VA system, and housing and education benefits.

Erlanger, et al. (82) note that while distinction between service- and nonservice-connected disabilities has always been made in discussions on veterans' benefits, the legitimacy of veteran pressure for benefits has never been seriously questioned. An examination of the hearings on the Veterans' Disability Compensation and Survivors' Benefits Amendments of 1980 supports this comment (215). The veterans' disability programs have always been separate from the civilian programs and have had better benefits and less strict eligibility requirements. The major issue of concern to policymakers has been the cost of the policy of providing all eligible disabled veterans with all necessary services (82).

#### Health and Medical Care

The major publicly financed health and medical care programs serving disabled individuals are programs that serve able-bodied individuals as well. They include Medicare, Medicaid, and VA medical services. Expenditures attributed to disabling conditions are significant. Berkowitz estimated that in 1977, \$1.4 billion was spent under Medicare and \$2.8 billion was spent under Medicaid (8). Another \$816 million was spent by VA. These figures do not represent total medical care benefits to disabled people funded under the three programs; rather, they represent only those medical care expenditures incurred by disabled persons directly related to their underlying impairments (8). Total health and medical care expenditures (not due only to disabling conditions) for disabled people under these programs are even higher. In fiscal year 1980, the Federal Government spent \$4.0 billion under Medicare for 3.3 million disabled beneficiaries, \$3.5 billion under Medicaid for 3.3 million disabled beneficiaries, \*

\*State supplements to the Medicaid program are not included in these figures.

and \$3.0 billion to \$5.6 billion for 0.6 million to 1.3 million disabled beneficiaries under the VA medical system (129). As will be discussed further, the use of technologies by disabled people is significantly affected by the amount of funds provided by these programs, either to individuals or providers, by the methods used to authorize payments, and by the organization of provision of services.

The Medicare program authorizes health insurance benefits to cover the cost of hospitalization and medical care for eligible elderly and disabled persons, including services by physicians, some allied health professionals, outpatient clinics, rehabilitation facilities, skilled nursing facilities, home health agency services, and some medically necessary drugs and devices (58,208). As noted in the previous section, individuals who are eligible for SSDI benefits for 24 months can receive Medicare benefits. Other eligible disabled persons include those severely disabled during childhood who are the dependents of deceased, retired, or disabled social security beneficiaries, disabled widows or widowers over age 50 whose deceased spouses were fully insured, and individuals with end-stage renal disease. Unlike the determination of eligibility process under SSDI or SSI during which medical factors, vocational factors and earnings were examined, eligibility for Medicare is strictly categorical with the categories mandated by statute. The determination process under this program is not as important for the use of technologies as it is under SSDI or SSI, although categorical eligibility clearly depends on the earlier determination process.

Under part A of the Medicare program (the hospital insurance program), participating hospitals, skilled nursing facilities, and home health agencies (institutional providers) are reimbursed for the reasonable cost of providing medically necessary inpatient and home care visits. The providers receive the reimbursement directly. Part A is financed by a payroll tax. Under part B (the Supplemental Medical Insurance program), reimbursement equals 80 percent of the reasonable charge for covered services, including physicians' services, outpatient physical therapy and speech pathology services, and other medically necessary services, including some drugs and devices. The

payments are financed by participants' premiums and by general Federal revenues. They are paid either to the providers directly *or* to those who receive the services (58).

The Medicaid program authorizes Federal payments to States to cover the costs of medical care and related services for eligible recipients. The program is administered by the State and financed jointly by Federal and State contributions; the Federal portion varies according to a formula that considers State wealth and according to participation in optional parts of the program. Most persons receiving SSI are eligible for Medicaid assistance (categorically needy). States *may* elect to use more restrictive criteria for Medicaid eligibility than SSI. However, States may elect to cover other individuals whose incomes are higher than the SSI maximum but who can not afford medical care (medically needy); Federal contributions are received for these beneficiaries. Participating States are mandated to provide certain services, including hospital and physician services, but they are permitted to provide optional services. The provision of prosthetic devices and rehabilitation services are considered optional services. The Medicaid program has emerged as a primary source of funding for services to disabled people. This is both because the incidence of disability is higher among low-income groups and because amendments to the act added specialized benefits for institutionalized mentally ill and mentally retarded persons (58). The primary example of such specialized benefits is the Intermediate Care Facilities for the Mentally Retarded (ICF/MR) program. The ICF/MR program was added to Medicaid in 1971 as an optional service; it will be discussed further below.

There are several important policy issues that affect eligible, disabled Medicare and Medicaid recipients. First, what technologies are covered and how are those decisions made? Under the present coverage mechanism, funds are passed from the Federal Government to contractors (called fiscal intermediaries for Medicare, part A, and carriers for Medicare, part B) who reimburse the providers. \* It is the contractors who are in-

\*The contractors may also reimburse individuals whether or not they have already paid the providers under the part B program. However, decisions on what is covered and what types of profes-

initially responsible for identifying coverage issues (166). When the contractors feel unable to judge whether *or* not to cover a particular service, the case is referred to 1 of 10 regional offices in the case of Medicare. If the regional office is unable to settle the issue, the case is submitted to the central office for a decision. Yet, decisions are often made on a case-by-case basis and thus may vary from region to region (or State to State).

Coverage for certain technologies (including procedures, services, and devices) is mandated by statute or regulation. For example, necessary curative physician services in or out of the hospital are covered nationwide. However, many individual technologies are not specifically covered in a list or set of lists.\*\* Their coverage depends on determination by the contractor that their use falls within a category of covered technologies. For example, prosthetic devices (a category of technologies) may be covered under part B of Medicare if they replace all or part of an internal body organ or replace the functioning of a permanently inoperative or malfunctioning organ (108). Communication aids, which are considered by numerous health professionals to be prosthetic devices, are not specifically covered under part B (47,108). At present, no agencies or programs are specifically mandated to fund the purchase of communication aids (108), although they may be covered under some programs once precedent-setting cases have been experienced. (See separately issued OTA Background Paper on "Assistive Communication Aids" for additional discussion on this topic. )

According to an earlier report by OTA (166), coverage decisions on a particular technology appear to be based on the technology's stage of development and its general acceptance. A technology that is perceived to have moved beyond experimental status to clinical application and to be accepted by the local medical community is considered "reasonable and necessary" and thus is

sions or institutions are recognized as providers are not affected by and do not affect whether *or* not the public funds are paid directly to the provider or to the individual.

\*\*Congress and the agencies often avoid such lists in drafting laws and regulations, because it is very difficult to be comprehensive. Usually some examples are included followed by phrases such as "other necessary services" or "other health impaired persons requiring special education and related services. "

covered if it is not specifically excluded from coverage. The standards for the criteria used—stage of development and general acceptance—depend on judgments made on the technology's medical safety and efficacy. These judgments are made by the contractors' or regional offices' medical advisors; they may be based on personal knowledge, on recent literature, or on advice by advocates of the technology (166). They are rarely made on the basis of a consistent national policy, and they vary widely from contractor to contractor (22,166).

Technologies that are covered must then be deemed "medically necessary" by the medical community for individual users. Lack of proof of medical necessity is often a reason for denial of funding even if the services are necessary for the comfort or convenience of the patient. Even if necessity is established, contractors do not always agree with clients and their providers over whether the need is medical in nature. Consultants employed to assist the contractors in their decisions rarely have experience with rehabilitation and do not fully understand its function. As a result, funding is often denied rather than justified. This is a particularly important problem for those disabled people whose needs for services and devices are not in response to curing a medical problem (even if it is a disease that has caused their impairment). Preventive services generally are also not covered. For example, a new electronic personal response system for disabled and elderly people that has been shown to be effective, called Lifeline (196), is not covered by Medicare or Medicaid because it is considered to be preventive but not "medically necessary."

A second issue affecting Medicare and Medicaid recipients is what types of professions and institutions are recognized as providers, because only those who are recognized as providers by law or regulation may prescribe the medically necessary services. While it may be clear to those outside the medical community that some technologies are medically necessary (and thus reimbursed), the recognized providers may not be the best suited to match a particular technology with an individual. The use of durable medical equipment (DME) may illustrate this point. DME, covered under part B of Medicare, refers to equipment

that: 1) can withstand repeated use, 2) serves primarily a medical purpose, 3) is not generally useful in the absence of an illness or an injury, and 4) is appropriate for use in the home (116,170). In 1977, an estimated \$73 million to \$130 million was spent on DME (115). Examples of DME include hospital beds and accessories, wheelchairs and accessories, and canes and crutches. For DME to be paid for, it must be prescribed by a physician. The prescription must include a diagnosis and prognosis of the patient's condition, the reason for prescribing the equipment, and the estimated duration of medical necessity (116). However, the actual matching of DME to the patient's needs is often done by providers such as social service workers, visiting nurses, orthotics specialists, and others who transmit the pertinent information to the prescribing physician. The carriers often check claims with these additional providers, and due to the number of individuals who must be contacted, the claims are up to five times more costly to process (169). There are, however, those who believe that the physician prescription is an important element in getting an appropriate fit between the technology and user and in obtaining funding (41). Although there are numerous other reasons for denial of funding, prescriptions that are not detailed are often initially denied or referred for followup. Carefully detailed physician prescriptions may, and have, assured funding (41).

Another problem pertaining to the issue of which providers are recognized for funding is that, although a class of institutions may be specifically recognized, the determination of whether an individual institution qualifies as a provider is not always clear cut. Thus, for example, intermediate-care facilities for the mentally retarded (ICF/MRs) were mandated as providers under the Medicaid program in 1971. While the law contained a definition of ICF/MRs, the definition was modeled on large publicly operated institutions for the mentally retarded. Initially, it did not specify criteria for including small publicly and privately funded community residences. Regulations promulgating the ICF/MR program in 1974 stipulated that facilities of 15 or fewer residents could qualify, but very little guidance was provided to States in certifying small community residences.

The updated regulations in 1977 were not much more specific (2).

A third issue affecting Medicare and Medicaid recipients is the amount reimbursed for the cost of covered, medically necessary technologies. The fact that a technology is covered does not ensure that it will be fully reimbursed. The amount authorized for Medicare or Medicaid reimbursement may be such that indigent clients needing expensive equipment (and, by definition, Medicaid recipients are indigent) may effectively be denied access to it (116). A study of DME claims flow and subsequent payment found that there was payment of only 52.3 percent of all submitted charges (116). The reasons for this figure included: a claims denial rate of 13.4 percent, requirements for deductibles and coinsurance, and reductions of the actual charges to allowed charges. The allowed charge is a result of a comparison among the actual charge, the customary charge of the individual supplier, the prevailing charge in the area, and the lowest charge level in the area for certain specified items (116). The Omnibus Budget Reconciliation Act of 1981 removed the Medicare reasonable charge limitations on Medicaid reimbursement. It is too early to assess the effect of this charge on indigent disabled people receiving technologies.

A recent GAO report on DME reimbursement found that standard DME items often cannot be bought at the amounts allowed and recommended that the lowest charge level screen be discontinued. That report also found inconsistencies in the reimbursement and coverage screens used in different regions of the country. The agency's recommendation was to make DME reimbursement policy more consistent (94).

A final important issue is that the Medicare and Medicaid programs have great influence on the type and location of services provided to disabled beneficiaries. Historically, reimbursement policies have promoted care in institutions both for disabled and elderly persons when coverage of home care and/or attendant services would have permitted some of those institutionalized to remain at home (2,14,66). While the current public policy rhetoric has shifted to a focus on community-based home health care, the policy reality is

that the incentives for institutionalization remain stronger than the rhetoric. One reason for this is that Medicare and Medicaid remain physician-driven medical programs to support curative care which were not designed to support the social (nonmedical) needs of beneficiaries (14). Most disabled individuals do not have a disease of which they may be cured. Another reason is that Medicaid eligibility may be easier to obtain when applicants are in institutions. In 16 States, disabled and elderly persons living in the community may not receive Medicaid unless their income is so low that they receive public cash assistance. These same persons can receive Medicaid with somewhat higher incomes if they are in nursing homes (66). An example may illustrate the incentives for institutionalization. While home health services are covered under Medicare, they may be provided only after an *acute* illness and to those who need skilled nursing care on an intermittent basis. This limited benefit is a very small part of the total Medicare program; in fiscal year 1979, only 2.1 percent of the Federal Medicare budget was expended on home health care (14). The home health aides who provide the service are not generally permitted to do housekeeping or general chores. Homemaker services, including chores, may be covered under Medicaid, although only 15 States have elected to do so (66).

VA provides comprehensive medical and rehabilitative services to all veterans with service-connected disabilities and to all veterans with non-service-connected disabilities who are unable to obtain or pay for needed medical services (208). Funding is 100 percent Federal. Unlike the Medicare and Medicaid programs, VA medical programs provide services directly in a variety of VA-run settings—including hospitals, nursing homes, domiciliary care homes, special rehabilitation centers for blind persons, and rehabilitative engineering and development centers. Priority for any services is given to veterans with service-connected disabilities. Veterans with nonservice-connected disabilities must prepare a statement declaring that they cannot pay for necessary medical expenses. This statement is used to establish an income limit for hospitalization, outpatient care, and nursing home care. Currently, approx-

imately 80 percent of VA patients are veterans without a service-connected disability (127).

Benefits provided include prehospitalization care, hospitalization, posthospitalization care, prosthetic devices, nursing home care, medical devices, transportation services, domiciliary care, outpatient medical services, and prescribed drugs. Unlike coverage decisions under Medicare and Medicaid, all technologies suited to a veteran's circumstances and needs are made available (123). Of course, determinations about circumstances and needs still need to be made. VA policy is to provide blind veterans with all necessary services and devices to overcome their handicap and to provide other disabled veterans with technologies deemed medically necessary. As with disability compensation and pensions, the major issue of concern to the users and policymakers is the cost of the policy of covering all available technologies. It should be noted, however, that there are funding restrictions for some services for veterans without service-connected disabilities. For example, a foster home program found to be effective is only available to those veterans who can afford to pay its cost with personal resources (149).

### Social Services

Social services programs serve disabled individuals by the direct provision of services, funding of services, or both, at the Federal, State, and local levels. The two programs with the highest level of funding are the Basic Social Services program authorized under title XX of the Social Security Act and the Developmental Disabilities program authorized under the Developmental Disabilities Assistance and Bill of Rights Act, as amended. Since the title XX and other social services programs serve the able-bodied as well as disabled individuals, it is difficult to estimate the expenditures for disabled people under these programs. Berkowitz provides a very rough estimate of \$841 million in 1977 (8). Total program expenditures were over \$2 billion. \* In fiscal year 1980, \$62.4 million was expended under the Developmental Disabilities program (122). There were approximately 3.6 million beneficiaries (184). \* \* Clear-

ly, the amount spent on these services is far less than that spent on income maintenance or health care services.

Social services comprise a wide variety of activities, including counseling, guiding, and informing individuals to enable them to use other public and private programs; referring individuals to other community resources; and providing identifiable services to individuals such as day care, personal attendant care, legal aid, and meals, which give them the opportunity to make use of other programs (208). The funds for social services programs may be used to pay for the programs' administrative costs, the providers' salaries, and actual physical objects needed by the programs' clients such as speech prostheses. The receipt of social services has been traditionally linked to eligibility for public income maintenance programs as well as some other measures of financial need. Individuals and families not receiving income from such programs may also receive services, although fees are usually charged if they have the ability to pay.

The title XX program authorizes Federal assistance to help States provide social services to public assistance recipients, including those who receive SSI. The Federal Government provides 75 percent of the funding (90 percent for family services and 100 percent for a portion of child day services) up to an appropriated ceiling. The funds are apportioned among the States on the basis of population. Within Federal guidelines, the States may establish eligibility criteria. Thus, while SSI and Medicaid recipients must be covered, other needy disabled people may be eligible. The States have broad discretion to define the services provided under this program as long as they meet one of five statutory goals: 1) achieving or maintaining economic self-support to prevent or eliminate dependency, 2) achieving self-sufficiency, 3) preventing or remedying neglect or abuse of children and adults unable to protect their own interests, 4) preventing or reducing inappropriate institutionalization, and 5) securing referral for or providing institutional care when other forms of care are not appropriate. Certain activities are specifically prohibited. These include major construction or renovation as well as medical or remedial services that can be funded under Medicare or Medicaid (unless such services

<sup>\*</sup>This figure was estimated using the fiscal year 1980 appropriation of \$2.7 billion (58).

<sup>\* \*</sup>This figure represents the estimated population of developmentally disabled persons.

are an integral and subordinate part of a broader service not supported by the medical programs) (58),

Although the breadth of the range of services that may be funded under title XX may mean that some clients receive a comprehensive program, it also means that providers and clients often need to learn the intricacies of the regulations in order to assure that necessary services are funded. This process is usually quite time-consuming. Another result of the wide range of possible services is that clients with similar situations in different States will receive different care. Finally, the range of services has resulted in title XX being used to fill gaps in funding services not completely paid for under other programs. Examples include radio reading services for blind people and otherwise print-impaired people (134), intermediate care facilities for mentally retarded individuals (2,14,39) and foster home care (66). This use of title XX funds exemplifies a significant problem in the total "system" of delivery and use of technologies for disabled people—a lack of coordination in funding and delivery of services. \* Furthermore, reliance on title XX funds to fill gaps in funding can be problematic, because unlike Medicare or Medicaid, title XX has a closed-end budget (14).

The Developmental Disabilities program authorizes Federal formula grants to States to support planning for services to persons with developmental disabilities. States also receive grants for the establishment of a system to protect the rights of developmentally disabled people. In addition, university-affiliated facilities for developmentally disabled persons receive grants to support their operation and administration. Special project grants to State and local public agencies and nonprofit organizations may also be awarded.

The current Developmental Disabilities program evolved from the Mental Retardation Facilities Construction Act of 1963. That act initially provided funds for construction of community-based mental retardation facilities and later supported the provision of comprehensive services (58). States are required by statute to select one priority service area out of the following: case

management services, child development services, alternative living arrangement services, and non-vocational social-developmental services. Under certain circumstances, a second priority area may be chosen. Services that maybe provided are similar to those authorized under the title XX program. Service activities, as defined by law, include delivery of services, model service programs, activities to increase the capability of agencies and institutions to deliver services, coordinating with other services, outreach, and training of providers ( 5 8 ) .

Eligibility for services depends on meeting the definition of developmental disability. Until 1978, a developmentally disabled person was one with a substantial disability attributable to mental retardation, cerebral palsy, epilepsy or other neurological conditions closely related to mental retardation that originated before the individual reached age 18 and was expected to continue indefinitely. In 1978, however, the definition of developmental disability was changed to shift the emphasis from etiological categories to functional impairments. The new definition includes disabilities attributable to mental or physical impairments that are manifested before the person reaches age 22 and result in substantial functional limitations in three or more of the following categories: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic sufficiency (58).

The change in definition of developmental disability was enacted by Congress after intensive lobbying by advocates of disabled citizens. While it is too early to definitively determine the effects of the change, there have been several significant occurrences (224,225). First, the original targeted population has been approximately halved, primarily due to the fact that mildly mentally retarded people are no longer being considered developmentally disabled. Second, the potentially eligible population has been broadened considerably due to the inclusion of physical disabilities and mental illness under the new definition. As a result, one State (so far) has withdrawn from the program. Another has specifically excluded chronic mental illness from the definition of developmental disability in the State

\*This problem will be discussed in depth later in this chapter.

statutes (2). Third, coverage of some of the services jointly funded under the Developmental Disability and Medicaid programs may have to be abolished due to the broadening of the definition. An example is the funding for the intermediate care facilities for mentally retarded people (who are developmentally disabled). The ICF/MR program was never intended to cover mentally ill or learning disabled persons. Thus, not only are funds insufficient, but the standards are not applicable to the new groups (2).

#### Education Services\*

The two largest programs that provide education services for disabled individuals are authorized under the Education for All Handicapped Children Act (Public Law 94-142) and the Vocational Education Act. In fiscal year 1979, the Federal Government spent \$951 million under the Education for All Handicapped Children Act's authority for approximately 3.9 million disabled children. States and local school districts added approximately \$5 billion to that amount (128). Under the Vocational Education Act, the Federal Government spent at least \$55 million in fiscal year 1979 for approximately 2.1 million special education students (132). \*\* State and local governments provide substantial supplements; in fiscal year 1979, they provided 91.5 percent of the total funds spent for vocational education programs (132).

Three additional programs, which will not be discussed in depth, are significant education services programs. \*\*\* Part B of title I of the Elementary and Secondary Education Act (Public Law 89-313) authorizes grants to State agencies operating or supporting schools for disabled children.

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\*Education services refer to those education services, such as elementary and secondary education as well as vocational training, provided and funded outside of the Federal-State Vocational Rehabilitation program.

\*\*This figure is for fiscal year 1978; it is an estimated figure. Special education students include disadvantaged and handicapped pupils.

•\*\*While there are many programs that provide education services for handicapped people, the Education for All Handicapped Children and Vocational Education Acts are those that serve the most disabled individuals. Thus, they were selected for highlighting in this report. Furthermore, problems and opportunities relating to those two programs are characteristic of problems and opportunities found in other smaller programs.

Federal appropriations for fiscal year 1980 were \$143 million (58). These funds supported over 222,000 children (122). The Handicapped Children's Early Education Act authorizes grants for demonstration programs for preschool disabled children and their parents. This program received \$20 million in fiscal year 1980 appropriations (122). It has been in existence since 1968. Finally, the Comprehensive Employment and Training Act of 1973 authorizes a number of programs to assist unemployed persons, including disabled persons, to develop job skills and work potential. While there are no programs specifically for disabled people, they were specifically recognized in the 1978 amendments to the act as a targeted population (58). During the Reagan administration, it is the training portion of the program that will be emphasized; appropriations for the employment programs have been substantially cut.

Basic education services for disabled persons, usually in the form of special education, were considered the primary responsibility of State and local education agencies until 1966. Congressional hearings that year revealed that only one-third of the country's disabled children were receiving appropriate educational services. Thus, a new title was added to the Elementary and Secondary Education Act (the Federal program of grants to States to support elementary and secondary education for all children) which authorized grants to States specifically to assist in the education of disabled children. In 1975, the Education for All Handicapped Children Act, as amended, expanded the original program to a major multibillion dollar commitment of the Federal Government to assuring all disabled children free appropriate public education in the least restrictive environment. Since enactment of the act, disabled children are to receive special education as well as any related services necessary to benefit from the education. An individualized educational program (IEP) is mandated for each disabled child (58). It is these provisions of the act that have significant effect on the use of technologies by disabled children.

The least restrictive environment (LRE) requirement is central to the act's mandate of a free appropriate education. The concept itself is simple—disabled children must be educated to the

maximum extent appropriate with nondisabled children. It is the word “appropriate,” however, which makes LRE a complex issue (49). Appropriateness is the factor that determines whether a child will be educated in the regular classroom or in another setting such as a special classroom, a special (separate) school, at home, or in the hospital or institution. The interpretation of appropriateness naturally varies from child to child, from school district to school district, and from State to State. In the 1977-78 school year, 93.9 percent of school-aged disabled children were educated in schools serving nondisabled children. Of those children, over two-thirds received educational services in classrooms along with nondisabled children. The proportion of children placed in regular schools and the proportion of those children placed in regular classrooms increased slightly over the previous year (49). \*

To keep these children in their current placements or to move them closer to a regular classroom, available technologies in the form of aids and services must be provided. Under Public Law 94-142, these aids and services are entitled “related services.” Determining what may be included as “related services” and who is responsible financially have been very difficult issues and certainly a source of confusion and long debate for policymakers, providers, and consumers. One reason for this difficulty is that the law and subsequent regulations suggest some examples of related services, but the list is intentionally not exhaustive (222). The examples themselves are not well defined; they include transportation, developmental and corrective services, speech pathology and audiology services, psychological services, physical and occupational therapy, medical services for diagnostic or evaluation purposes, school health services, social work, and parent counseling and training (194). Decisions on what may be included under each example category still need to be made by local and State agencies and, ultimately, the courts. For example, a case on whether catheterization (a medical service) must be provided is still being fought in the courts; the

current status is that States do not have to provide that service (222). A second reason that “related services” has been a difficult issue is that education agencies now have the responsibility for providing services that have historically been the domain of the medical community (194). Under Public Law 94-142, a child needing physical therapy would have that need determined by a team of educators instead of the traditional physician. In many States, a physician would still need to prescribe the physical therapy services\*\* (without having first determined the need) and then have that prescription’s outcome subject to an educational fair hearing process.

The mandate that each child must receive an IEP clearly affects the delivery and use of technology, since it is the IEP that details the current capabilities of the child, the annual and short-term instructional goals, the particular services to be provided, and the extent to which the child is to participate in the regular classroom program. Related services are prescribed in about 13 percent of the IEPs (49). One issue relating to the IEP that is often discussed is the cost of its development. Those who believe it is too costly due to the number of hours and personnel needed\*\*\* argue that the requirement should be deleted unless Federal funds are allocated specifically for that purpose. Others argue that its cost is only too high if the IEP system is placed on top of the placement and classification systems already in place and that, ultimately, less professional time might be needed than under the former placement systems (128). Another issue relating to the IEP concerns the methods by which it is developed (49,171). On one hand, the IEP process requires a move towards educational programming and use of related services based on a functional assessment of an individual child’s abilities and disabilities and away from special education classes for categories of disabled children (such as “mentally retarded” or “deaf”). On the other hand,

● \*In these States, the Medical Practices Act does not allow physical therapists to provide services without a medical prescription (194).

\*\*\*A national survey of IEPs found that there was an average of 4 participants in the development of IEPs, with the greatest number reported as 15. These participants included representatives of the school district (usually principals), special education teachers, regular classroom teachers, physical and / or occupational therapists, speech therapists, school psychologists, social workers, school counselors, parents, handicapped students themselves, and others (49).

\*The increase does not necessarily represent a change in policies or implementation relating to the least restrictive environment requirement, but rather may represent an increase in the number of mildly handicapped children served.

however, the IEP process in its focus on the individual child tends to devote too little time to an assessment of the child's environment as a continuing source of the handicap.

While studies of the implementation of Public Law 94-142 indicate that more disabled children are receiving a free appropriate education than ever before (49), there is evidence suggesting that the congressional intent remains unfulfilled. It does not appear that all disabled children are being served. Seven percent of school enrollees are disabled, yet 12 percent of the total school-aged population is disabled (17). (Keep in mind, however, the frequently inadequate state of data in the disability area.) Many of these disabled children who are enrolled in school remain unnecessarily segregated in special classes or whole schools (77). There appears to be a substantial yet undetermined number of children who need but who do not have access to special education (93). In addition, disabled children are often denied essential related services; in some school districts, related services provided have been based on what was available instead of what was needed (49,77). A number of disabled children are waiting for an IEP (77). Others are reportedly suspended for periods of up to 2 years (77). There continue to be shortages of adequately prepared special education teachers and support personnel (49,128). Finally, while the law guarantees rights to disabled children and their families, the funds for its enforcement have been called inadequate (16,121). (See separately issued Background Paper for a case study on "The Educational Context and the Least Restrictive Environment" for a more complete discussion of Public Law 94-142.)

The Vocational Education Act, as amended, authorizes a program of grants to States to support vocational education. While the Federal Government has supported State vocational education programs since 1917, it was not until 1963 that the funding structure and legislative language recognized the needs of special groups, including disabled people, and not until 1968 that disabled people were specifically targeted as beneficiaries. In 1963, the focus of Federal funding shifted from support of occupation-specific training programs to support of general planning for and operation of a wide range of secondary and postsecondary

vocational education programs and auxiliary services (48). This shift allowed States to develop programs that included disabled and disadvantaged students who had been excluded by virtue of the types of occupation-specific programs previously provided. Since 1968, 10 percent of each State's basic grant funds must be targeted to disabled students. In addition, Federal funds (\$20 million in fiscal year 1981) are appropriated for special programs for disadvantaged students (132).

Although specific devices are not provided with vocational education funds, vocational education programs are important for the use of technologies by disabled students, because effective use of technologies in the employment setting is one objective of the education services received. In addition, vocational education programs often serve as a source of information on what technologies are available to assist disabled individuals in employment. Evaluation of the effects of vocational education programs on their students is quite difficult, because many factors other than the program curriculum affect the economic and noneconomic experiences of the students once they leave the programs (48). One report on the state of the art of vocational education of disabled students (112) identified six areas needing improvement: 1) interagency cooperation, 2) personnel preparation, 3) amount of funding, 4) availability of a choice of service delivery and program options for disabled students (i.e., regular vocational education programs, adapted programs with special support services and materials, special education programs, or individualized vocational training in a variety of settings), 5) program evaluation, and 6) delivery of services to Native Americans and other minority disabled youth. Another report found that it is necessary to look at programs not necessarily designated as vocational education programs since most special education courses for postelementary students have vocational content (159).

From a national perspective, there are several issues of concern regarding the Vocational Education Act and disabled people. Bowe has stated that vocational education is the most blatantly discriminatory aspect of public education, since only 1.7 percent of those receiving vocational education services are disabled while 10 to 12 percent

of the population eligible by age are disabled (17). He reported that this discrimination has been due to a lack of appropriations for monitoring and enforcing the full access requirements of the law. Additional factors have been suggested as contributing to the low percentage of disabled enrollees, including severe shortages of personnel training in both special education and vocational education, limited types of vocational education programs and service delivery options, and a limited funding base (112). Another issue of concern is that the procedures mandated for the States to distribute Federal dollars to local education agencies and other eligible recipients are extremely confusing and, in part, contradictory (48,132). One set of criteria is used for determining the priority of applicants and another set, similar but not the same, is used for distributing the funds. This situation exists because the Education Amendments of 1976, which amended the Vocational Education Act, combined a Senate bill with a House bill without reconciling them. A third issue is whether the Federal Government should continue its involvement in vocational education. Arguments against continued involvement include noting that more services are being provided with a smaller percentage of Federal funds each year. Arguments for continued involvement include noting that only the Federal program have required planning for targeted populations and that relatively small amounts of Federal funds have been effective in advancing Federal goals and affecting and/or redirecting State efforts.

#### Vocational Rehabilitation and Independent Living

The stated goals of the vocational rehabilitation system are: 1) to assist vocationally disabled individuals to enter or return to gainful employment and 2) to assist those individuals whose disabilities are so severe that they do not have the potential for employment, but who may benefit from services, to live and function independently. The Rehabilitation Act of 1973, as amended, authorizes a variety of service, demonstration, research, and training programs to accomplish these goals.

The largest program provides Federal grants to designated State rehabilitation agencies to provide basic rehabilitation services to disabled persons.

The Federal Government provides 80 percent of the funding for the Federal-State program (208). In fiscal year 1980, \$1.4 billion Federal dollars were spent for 1.1 million beneficiaries (130). Eligibility for vocational rehabilitation services is usually determined by a rehabilitation counselor, in consultation with the client, based on meeting three criteria: the presence of a physical or mental disability, the presence of a substantial handicap to employment, and a reasonable expectation that the vocational rehabilitation services will allow the individual to become gainfully employed. For each client accepted, an individual written rehabilitation plan must be developed. This plan defines the individual's long-range employment goal and lists the specific intermediate services to be provided to achieve the goal.

In addition to counseling and guidance, the vocational rehabilitation client may receive physical and mental restoration services; prevocational evaluation and training; vocational and other training services, including personal and vocational adjustment services, books, tools, and other training materials; maintenance allowances during the rehabilitation process; transportation; services to the client's family if they are necessary to the adjustment of the client; interpreter services for deaf persons; reader, orientation, and mobility services for blind clients; telecommunication, sensory, and other technological aids and devices; work adjustment and placement counseling; placement services; occupational licenses, tools, equipment, initial stocks, and supplies; and any other goods and services which may reasonably be expected to assist in the employment of a disabled individual (58). In essence, then, any technology that can be proven to be of value in preparing an individual for employment or in maintaining that employment may be provided under this program. The goods and services are provided by the State rehabilitation agencies themselves, by other public service agencies, and by private agencies who serve the general public. They are paid for out of the Federal-State vocational rehabilitation funds unless the individuals are eligible for support under some other program (208). An example of another program is the Beneficiary Rehabilitation Program funded under the SSDI program.

The key issue in the vocational rehabilitation program is eligibility, since the range of technologies available to and funded for eligible disabled individuals is clearly extensive and varied. By mandate, vocational rehabilitation agencies now must focus attention on severely disabled people. Yet a possible conflict with this requirement is the eligibility criterion that requires evidence of a reasonable expectation that rehabilitation service will result in gainful employment. In 1975, the Urban Institute (208) found that only 41 percent of all vocational rehabilitation recipients could be considered severely disabled. The same study noted that critics of the system suggest that rehabilitation counselors select the least disabled persons eligible to receive services to increase the number of successfully rehabilitated clients. Although this criticism has been difficult to test, it is known that services do fail to reach many who need them or may benefit from them. Bowe pointed out that of every 11 individuals eligible for vocational rehabilitation by virtue of their disability, only 1 is served (17). The primary reason behind limiting eligibility for services appears to be a lack of enough appropriated funds, both Federal and State.

Vocational rehabilitation services for severely disabled people tend to be provided in programs at work activities centers, developmental centers, other sheltered workshops, or at independent living centers. A sheltered workshop may be defined as a vocationally oriented rehabilitation facility that utilizes work in a structured, controlled environment to provide evaluation, training, and employment and is designed to assist disabled persons to move to their optimum level of production (223). Workshops differ in the type of clientele served, the production-rehabilitation orientation, the placement in competitive industry, the type of goods produced, the consumers to whom goods are sold, and the capital-labor mix used in production. Sheltered workshops that provide services to a number of vocational rehabilitation clients are largely funded with Federal-State vocational rehabilitation moneys. However, many sheltered workshops serve clients considered too severely limited for vocational rehabilitation eligibility (60). Sheltered workshops have been studied extensively. Issues of concern include the dual

role of the disabled person as client and employee and the resultant problems, funding for construction and operations, the lack of movement of disabled clients from the workshop to the competitive labor market, the determination of a proper amount of wages to workshop employees, the development of a fair yet little time-consuming process for determining eligibility for the subminimum wage requirement to encourage employment opportunities, and the need to strengthen enforcement of the Fair Labor Standards Act (60,98,223).

The Rehabilitation Act also authorizes formula grants to State vocational rehabilitation agencies to provide comprehensive independent living services to those disabled individuals who do not have present potential for employment. This authority was created in the 1978 amendments to the act in recognition of the needs of many severely disabled people who were unable to qualify for vocational rehabilitation services. "Independent living" is a concept with a variety of definitions, although the following ideas seem to be important generic components: individuals make their own decisions and are responsible for their own lives; individuals are integrated into the community to the maximum extent feasible or desirable; and individuals have access to support services in order to maintain independence. Independent living services are those services that make independent living possible; the kind and amount necessarily vary from person to person. Housing, however, can be viewed as a central theme around which other independent living services and issues resolve (206). It is included as an allowable service under the independent living authority of the Rehabilitation Act. Other allowable services include counseling, modification of existing housing, appropriate job placement services, transportation, attendant care, physical rehabilitation, therapeutic treatment, needed prostheses and other appliances and devices, health maintenance, recreational activities, services to children of preschool age, and appropriate preventive services to decrease the need for future services.

Since the allowable services appear comprehensive enough to permit attainment of independent living, eligibility for services should be the

primary issue of concern with respect to the use of technologies. However, the independent living formula grant authority received no appropriation for 1980. There was \$15 million appropriated for project grants to vocational rehabilitation agencies to establish and operate centers for independent living which provide or arrange for many of the activities listed above (58). However, this level of funding does not actually pay for the necessary services, and centers for independent living must spend huge amounts of time obtaining other funds. It should also be noted that the Federal policy of deinstitutionalization of mentally retarded persons (as discussed earlier) has increased the need for independent living services (223). Appropriations for this authority may be needed now more than ever.

### Nonpublic Programs

Activities concerned with the delivery, use, and financing of technologies for disabled people in the nonprofit and private sectors are numerous and varied. Since the 1930's, developing and assuring the delivery of services has been primarily a public (governmental) sector activity. The availability of public funds in support of public policies has greatly shaped the nonpublic sector. Nonprofit and private agencies and organizations, however, are often the actual service providers under public programs. In addition, they provide services and funding not covered by the public programs.

The major activities in the nonprofit and private sectors are sponsored by volunteer agencies with specialized fundraising activities tied directly to disabling conditions, by fraternal and religious societies, by veterans' groups, and by self-help and consumer organizations (83,201). In addition to service provision, an important function carried out by nonprofit organizations is the coordination of various public sector programs. Disabled individuals are often eligible for more than one public program, yet they do not have the information or the resources to take full advantage of available services. A number of nonprofit organizations serve as information and resource brokers, matching their clients with the appropriate public programs.

Private insurance companies provide income maintenance benefits to certain workers unable to work due to disability. The amount of benefits varies, depending on whether the disability is (in their language) "total" or "partial" and the period of time for which benefits are payable. The duration of benefits usually depends on whether the disability was caused by an accident or by an illness. This feature of private disability income protection insurance differs from the SSDI program under which eligibility does not depend on the cause of disability. Private disability income coverage is either short-term or long-term. Short-term policies provide benefits for up to 2 years, while long-term policies provide benefits for specified periods such as 5 years, 10 years, or to age 65. In 1979, 84 million individuals had some form of disability income coverage. Of these, 66 million had short-term policies, and 20 million had long-term policies. More than 2 million people had both types of coverage (107). (These figures include those covered under public programs.) The total benefits paid under these programs, although substantial, are far less than those paid under the Federal programs. In 1977, insurance companies paid just over \$2.2 billion (106). Disabled beneficiaries of private plans often seek coverage under the public programs once benefits run out.

Private and nonprofit insurance companies have traditionally covered disability-related health and medical care; in 1977, Blue Cross-Blue Shield spent an estimated \$5.3 billion for those expenses. However, many insurance companies have avoided or limited coverage of preventable or remedial rehabilitation services under their medical care policies. One method used to limit coverage is the exclusion of any education or research costs performed by hospital staff. Often, rehabilitation services fall under one of those categories. Reasons cited for these exclusions include the problem of defining the eligible populations; the difficulty in selecting limits to eligibility on an individual basis once the eligible populations have been defined; the difficulty in determining cost, cost benefit, or cost effectiveness of services; the need for new methods of data collection; the need for an analysis of past experience; and the need for evidence of meaningful utilization review mechanisms (143,201).

In recent years, an increasing number of companies have become involved with rehabilitation services coverage. Part of the increase is due to the efforts of the Insurance Rehabilitation Study Group (IRSG). IRSG, founded in 1965, is a group of 50 insurance company executives who are actively engaged in rehabilitation and medical administration. Activities of the group include maintaining awareness of current rehabilitation principles and practices, developing innovative policies, and providing information to the public (144). Membership is on an individual, not company, basis, but the influence of the members on their parent companies is continuing to be demonstrated.

In contrast to the slower development of rehabilitation coverage by insurance companies, organized labor benefits have been more comprehensive and have been steadily increasing, especially through the larger labor unions (201).

The volunteer agencies have played a significant role in increasing public awareness of the problems of disabled individuals, in raising private funds, in advocating legislation, and in assisting to provide program services (201). Some agencies have started handicap industries that employ severely disabled people. These industries

are privately owned companies that compete for profits in the competitive labor market (profits usually accrue to the nonprofit agency that established the company) and that employ disabled and able-bodied workers side by side in the production process (32). An example of a handicap industry is Center Industries Corp., a manufacturing company founded by the Cerebral Palsy Research Foundation of Kansas; this company has often been cited as a model program and company. Furthermore, a study of the economic costs and benefits of employing severely disabled people at Center Industries found the net benefit per worker to be positive (32).

Finally, the university centers that provide services and perform research and training can be considered programs in this sector. These include rehabilitation engineering centers and rehabilitation research and training centers described in chapter 6 as well as the university-affiliated facilities funded under the Developmental Disabilities program. However, the bulk of funding for their activities comes from one or more of the public programs discussed earlier, and, thus, their effect on the delivery and use of technologies by disabled people is largely a function of public policies.

## DISCUSSION OF GENERAL ISSUES

In addition to those issues previously discussed, there are several others, not related to particular programs, that affect the use of technologies by disabled people. They may be arbitrarily grouped as follows: 1) the coordination and consistency (or lack thereof) of services and funding, 2) the gaps in enrollment for public and/or nonpublic programs, 3) the difficulty in maintaining medical/rehabilitative device technologies, 4) consumer involvement in service delivery, and 5) the shortage of rehabilitation providers.

### Coordination and Consistency of Services and Funding

A common problem, often raised in the literature and in personal interviews, is that services and funding for disabled people come from

so many different, often uncoordinated, sources that users and providers are either unable to take advantage of available technologies or must spend enormous amounts of time providing the coordination needed to best assist each individual. This lack of coordination and consistency has meant that resources are often spent inefficiently and sometimes ineffectively. Furthermore, individuals with similar problems do not receive similar amounts or types of assistance (205). The primary underlying reason for this lack of coordination is that the pieces of legislation supporting the various programs were developed separately (usually by groups of advocates). Each advocate group usually had different objectives in mind for what need each program should fill, how it should be administered and funded, how its services should be delivered, and whom it should serve. In addi-

tion, Federal policies regarding disabled persons have focused on limited areas of people's lives (e.g., income maintenance or education or work), and laws and regulations stemming from such policies have been drafted without enough analysis of their effects on the other areas (39,217).

The definitions of disability, including age limits used in determining eligibility for services, may foster the lack of coordination. Most laws define eligibility based on determinations that individuals have one or more etiology-specific categories of impairments (e. g., cerebral palsy, mental retardation, or lack of vision). Thus, two individuals with different "categories" of disability but who both need technologies to assist in mobility may be eligible for different programs. A number of steps involving several agencies and providers (and a lack of continuity) maybe taken until the individuals' actual needs are met. Some advocates for disabled persons favor changing the definitions in the laws or regulations to reflect functional disabilities (as in the current developmental disabilities legislation) instead of categorical disabilities, in order to remove this barrier to coordination. These advocates maintain that the presence of categorical programs causes duplication of effort and wasting of scarce resources. In addition, it necessitates labeling of disabled people which, because of the stigma associated with being "handicapped," may then cause their exclusion from opportunities necessary for their full development as individuals and in society (110). Furthermore, the existence of categorical legislation helps sustain organizations oriented to one disability that compete for the limited resources and services available to disabled people (19,131 ).\* Advocates for cooperation and coordination believe that such cooperation will assist all disabled people receive better services. However, attempts to "decategorize" the definitions in current legislation have been met with resistance from the advocates of particular categorical disabilities who are well served by the legislation and who claim that diversity of self-interest is a productive and efficient approach to obtaining necessary resources (201). Those who have learned to function well within

the current system are also reluctant for change (201),

The lack of coordination both causes and is caused by the structure of the service delivery, "system." At the overall societal level, separate systems of service delivery have developed in areas pertinent to disabled people, such as health and medical care, education, and social services. Recent legislation (Public Law 94-142, for example) mandates that eligible individuals receive assistance from each of these systems, yet professionals within the systems are unaccustomed to, and thus, reluctant to and/or ineffective in, working together (200,217). At the level of individual providers, the standard behavior of professional autonomy fosters discontinuous care. Individual providers, particularly physicians, know little about other resources within the community with which to assist their clients once their services are no longer needed (154).

Funding for the same or similar technologies is often available under various programs, each with different rules for payment. This inconsistent and confusing situation leads to the expenditure of a great deal of energy and time on locating funding for individual clients or programs. There are numerous examples of manuals developed on how to obtain funding for a particular technology. These are written by researchers, advocates, users, and even manufacturers (47,134,178,192). Similarly, much time may be spent learning how to make the most of funding under one program, given the complexity of the regulations. The title of a manual to assist program administrators, *Roadmap Through Title XX*, provides an illustration of this problem (40).

Services provided, and eligibility for those services, often differ from State to State, even under the same program. This lack of consistency hampers the dissemination of information about technologies and how to gain access to them, because the information is not transferable across State borders. DeJong and Wenkler (46) illustrate the often confusing differences between States through the example of attendant care services, a technology needed by all quadriplegic and many other individuals who use wheelchairs to live independently. Attendant care services are those

\*It should be noted, however, that the uni-disability organizations were very influenced in the development of the current type of legislation.

tasks performed by an attendant in assisting a severely disabled person with basic activities of daily living. These services are needed by approximately 2.9 million Americans. Yet because of the cost, which runs from minimum wage to \$5 to \$6 per hour for an average of 6 hours per day, many individuals cannot afford these services without public assistance. A citizen of Massachusetts can receive attendant care services if he or she is over 18, limited in the upper extremities, psychologically and medically stable, and eligible for Medicaid. Medicaid eligibility is determined by the public welfare department, while determination of eligibility specifically for attendant care is made by one of three independent living centers. If, in addition to attendant services, the attendant performs housekeeping services, the time may be billed to Medicaid. If the citizen were in Minnesota, however, the housekeeping services would have to be separately billed to the State's title XX program, if the individual were eligible. In California, all attendant care services, including housekeeping, are funded under title XX; thus, only those eligible for title XX may receive publicly funded attendant care.

### **Gaps in Enrollment**

The Urban Institute study (208) noted that quite a bit is known about those who are served by programs for disabled people, but very little is known about those who do not receive services because they fall through gaps in eligibility for public and nonpublic programs. However, it has been well documented that gaps exist (82,110,201,205,208). Indeed, NIHR has as one of its research issues the development of service delivery techniques to prevent clients from "falling through the cracks" (53). Disabled people who fall into such gaps may be those who are multiply-disabled and as such do not fit neatly into a categorical program (110), as well as those who by some measure fall on the wrong side of the border between "disabled" and "not disabled" under existing program definitions (e.g., those who earn slightly over SGA or those whose vision is bad enough to need special devices and services but who are not quite "legally blind"). In addition to the problem of gaps due to definitions of eligibility, there are gaps in the provision of technologies to unenrolled but eligible in-

dividuals. This problem appears to be partly due to a lack of public awareness, partly due to a lack of outreach efforts to correct it, partly due to the lack of systematic method to correct it among uncoordinated programs, and partly due to the system's inability to handle all eligible clients because of a shortage of funds and personnel (154,201).

### **Maintaining Medical/Rehabilitative Device Technologies**

Once disabled individuals obtain needed technologies, maintenance can be a serious problem. The users must be able to obtain parts for their device, locate skilled repair workers, devise a way to function while the device is being repaired, and pay for the whole process. For example, most battery-driven wheelchair users must maintain a second chair for the times when their primary chair is being repaired, because even the simplest repairs can take months. In addition, the average power-chair user spends \$900 per year in maintenance and repair fees (141).

Not surprisingly, the difficulty or ease with which these steps are taken varies from device to device. Maintenance costs and availability may depend on whether the device is manufactured by a large company, by a small company, or nearby, so repairs are relatively easy to arrange. However, these devices are generally prototypes and thus, more prone to failure, so repair cost and lack-of-use time may be high. Devices manufactured by small companies often come from far away; repairs may be hard to arrange locally, and shipping the device back to the company is costly and time consuming. Users of devices manufactured by large companies generally have the easiest time with arranging repairs. These companies often establish service centers across the country staffed by personnel trained in fitting the devices as well as personnel trained in servicing them (117). For example, Phonic Ear/Phonic Mirror has more than 75 locations where their devices can be fitted (177). All users, however, face the problem of repair costs. Some insurance companies are concerned about equipment maintenance and repair and cover these services in their policies. These provisions vary from contract to contract. Unfortunately, those with the most comprehen-

sive policies are often those who receive the highest disability income maintenance payments.

### **Consumer Involvement in Service Delivery**

Consumer involvement is as important an issue in the delivery and use portion of the technology lifecycle as it is in the R&D portions, because it is primarily the disabled consumers of technologies who have the level of understanding and experience to ultimately assure appropriate delivery and use,

The term “consumers” may be narrowly defined as the disabled or handicapped individuals who receive a service or commodity from a service program and thus are clients of that program. However, the term may be defined more broadly as those affected directly or indirectly by the rehabilitation system, including disabled clients, families of disabled clients, former and future clients, those who qualify as clients by virtue of their disability but who do not receive services, and persons who represent the interests of the disabled (advocates). Consumer involvement currently occurs both at the individual level (see the narrow definition) and at the program and society levels (see the broad definition). At the individual level, disabled people participate in the creation of IEPs under the Education for All Handicapped Children Act. At the program level, disabled people themselves as well as those affected by the rehabilitation system participate in advisory boards that formulate or affect program policies. Under the Vocational Rehabilitation System, there are statewide advisory boards composed of elected representatives from organizations of disabled persons that review the policies of the State’s rehabilitation agency. At the society level, consumers as defined broadly comprise the National Council on the Handicapped. The National Council is mandated to review all policies, programs, and activities concerning disabled persons conducted or assisted by any Federal agency (58).

The preceding examples of consumer involvement were all mandated by legislation passed in the last decade. They are considered positive steps by advocates of disabled people, because they reflect consumer input at a policy level (18).

Previous (and still, in many cases, continuing) approaches to consumer involvement have included newsletters, public hearings, other methods of informing consumers about public program activities, and use of disabled consultants in preparing annual reports and State plans. These approaches have been called inadequate (18). While particular programs for consumer involvement have been neither legislated nor regulated, avoidance of tokenism remains an area on which States must continue to focus in developing programs for policy development consultation by disabled persons.

While current legislation and regulations represent advances in consumer involvement in services delivery, there are several areas that still need improvement. Only half of the State vocational rehabilitation agencies have written plans for consumer involvement. The remaining States need to develop such plans to assure that the legislative requirements are being met. A survey by the American Coalition of Citizens with Disabilities (18) found that consumer advisers were not always representative of rehabilitation agency clients. Mechanisms to assure representation of the clients served in making policies about services must be developed. Finally, the number of areas and activities in which consumers are involved must be constantly assessed and broadened in order that the ultimate goal of consumer involvement—better and more effective services—is achieved.

### **Shortage of Rehabilitation Providers**

It has already been noted that only those providers recognized by law or regulation may prescribe technologies that are paid for by public (and most private) funding and that these providers may not always be the ones best suited to matching particular technologies with individuals. However, another problem is a shortage of these providers, albeit they may not be the desired types.

In the medical area, there are relatively few rehabilitation medicine physician specialists, (physiatrists\*), although specialty medical boards have existed in this area since 1948. In 1971, there

\*This is not a misprint. The term is “physiatrist.”

were close to 1,500 rehabilitation specialists, or 0.4 percent of the 334,000 physicians in the United States (150). In 1976, this number increased to 1,715, but the percentage remained approximately the same (181). The Interim Report of the Graduate Medical Education National Advisory Committee (102) predicts that the percentage will be the same in 1990. There have been various estimates of need made (150,181) that differ in terms of assumptions but which all lead to a similar conclusion—there is and will continue to be a substantial shortage of rehabilitation medicine physician specialists through 1990. Estimates for demand in 1990 range from 4,000 to 4,900, while estimates for supply range from 3,380 to 2,900. It should be noted that other physician specialists do provide rehabilitative care, although there are no readily available measures of their numbers. It is usually the rehabilitation physician, however, who is trained to perform the broadest range of rehabilitation services, including providing direct rehabilitative services as well as organizing systems of care in the community, obtaining resources, conducting research, and providing education on disability (181).

One reason for the low number of rehabilitation physician specialists is that the specialty is perceived as one with low status, perhaps in part because of the high proportion of foreign medical graduates who enter it. In 1976, 65 percent of the first year residents in physical medicine and rehabilitation were foreign medical graduates (181). Conversely, it has been suggested that the area has a high proportion of foreign medical graduates because it is a low status specialty for “other reasons,” and foreign medical graduates thus find it easier to enter than other areas of medicine.

One of these “other reasons” maybe that a physician in rehabilitative medicine has less control than physicians in most other specialties owing to the wide range of other professionals (e.g., vocational rehabilitation counselors, occupational therapists, teachers) who enter into decisions or whose opinion must be taken into account. Second, medicine is a “cure-oriented” profession, and conditions that are stable or deteriorating assault that professional orientation. Third, it maybe that rehabilitation medicine receives a low priority in

general hospital settings. A study of VA rehabilitation medicine services found that 29 percent of those services were understaffed in support services. The reason proposed was that the support staff (nurses, social workers, psychologists) were under the control of chiefs of service other than the rehabilitation medicine chief, and those chiefs may give the rehabilitation medicine services a lower priority than other services such as medicine or surgery (149). A final reason for the low status of rehabilitation medicine is that professional orientation begins in medical school, where there are few courses on the management of chronic or ongoing disability. Basic physician training does not usually include learning how to refer to available community resource agencies or how to assess the need for such services—skills that every physiatrist uses often.

If the number of rehabilitation physician specialists cannot be increased for the preceding reasons, alternatives might be to increase acute care physicians’ skills in rehabilitation or to develop service delivery mechanisms that depend more on related health and disability professionals. Training in these skills is possibly best done during the residency program (because the medical school program is already lengthy); however, it is necessary that orientation toward chronic, ongoing conditions begin in medical school.

There are a number of other types of providers involved in the provision of goods and services to disabled people, including physical therapists, speech therapists, occupational therapists, rehabilitation counselors, vocational educators, rehabilitation engineers, independent living center staff (e.g., peer counselors), orthotic and prosthetic technologists, and social workers. These allied health providers are often paid by institutional providers, including State vocational rehabilitation agencies, education agencies, comprehensive rehabilitation centers, hospitals, etc., recognized under one of the funding authorities. While the number of allied health professionals has increased dramatically over the last 30 years, a shortage remains (60,150). The shortage based on needs as perceived by disabled people is difficult to quantify precisely because demand figures

include estimates of demand from individuals who would not be included as “disabled.” However, it is predicted that as the implications of legislation such as the Education for All Handicapped

Children Act and the Developmental Disabilities Amendments of 1978 become more apparent, the demand for and the shortage of allied health personnel will increase (60).