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Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

PROGRAMMATIC DEFINITIONS OF DISABILITY: POLICY IMPLICATIONS

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Office of the Assistant Secretary for Planning and Evaluation

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The Office of Disability, Aging and Long-Term Care Policy (DALTCP), within ASPE, is responsible for the development, coordination, analysis, research and evaluation of HHS policies and programs which support the independence, health and long-term care of persons with disabilities--children, working aging adults, and older persons. DALTCP is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

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This paper was prepared by HHS's Office of Family, Community and Long-Term Care Policy (now DALTCP). For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The Project Officer was Michele Adler.

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TABLE OF CONTENTS

I. BACKGROUND AND PURPOSE	1
II. OVERVIEW OF RESEARCH AND PROGRAMMATIC DEFINITIONS OF DISABILITY	2
III. OVERVIEW OF FEDERAL DISABILITY PROGRAMS	4
IV. SPECIFIC PROGRAM DEFINITIONS AND DESCRIPTIONS	5
A. ADA	5
B. SSA Definition.....	5
C. SSDI	5
D. SSDI Eligibility Process.....	6
E. SSI	8
F. Medicare	9
G. Medicaid	9
H. Black Lung	10
I. VA Disability Compensation and Pensions	11
J. Veterans' Health Services.....	11
K. CHAMPUS for the Handicapped.....	11
L. Social Services Block Grant.....	11
M. Administration on Developmental Disabilities	12
N. Maternal and Child Health Block Grant--Programs for Children with Special Needs.....	12
O. Alcohol, Drug Abuse and Mental Health Services Block Grant.....	13
P. Department of Education's Educational Program	13
Q. Basic Vocational Rehabilitation Services	14
V. CONCLUSIONS	15
VI. REFERENCES	16

LIST OF TABLES

TABLE 1: Major Federally Financed Disability Programs	18
TABLE 2: Definitions of Disability	19

I. BACKGROUND AND PURPOSE

This paper looks at programmatic definitions of disability for Federal disability programs by: (1) reviewing and examining major programmatic definitions of disability; (2) describing complex eligibility processes by using the Social Security Disability Insurance (SSDI) program as an example; and, (3) discussing how some proposed changes in program definitions might affect future policy.

Massive amounts are spent on Federal programs targeted on persons with disabilities. In FY 1989 \$85 billion or 8 percent of all Federal outlays was spent on disability programs targeted JUST on nonelderly persons with disabilities. Admission onto Federal programs is determined by how disability is defined programmatically and which specific eligibility criteria are employed.

Disability is notoriously hard to define and definitions vary widely. The many Federal disability programs who is eligible to receive benefits, who is not, who could in the future, and who would be if program modifications were made. Differences in programmatic definitions result in wide variations in the number and characteristics of persons eligible to receive benefits and huge difference in how much programs cost.

Measures from population-based surveys often serve as the basis for estimates of participation in Federal programs. These measures are perhaps hardest to derive for disability programs, because disability. For example, the purpose of the SSDI program is to provide monthly cash assistance to disabled workers under 65 and (in some cases) to dependents. In 1984, 3.1 million persons received SSDI benefits. According to the 1984 SIPP, measures of functional disability range from 21.7 million (those with any functional disability) to 3.2 million (those with an ADL/IADL limitation).

Finally, programmatic definitions are dynamic, with changes occurring due to amendments to the law, new regulations, and court decisions which may either modify programmatic definitions or eligibility criteria.

II. OVERVIEW OF RESEARCH AND PROGRAMMATIC DEFINITIONS OF DISABILITY

Research definitions of disability are also hard to define, because so many aspects of human behavior (medical, social, and cultural) are involved. Definitions again depend on context. Disability is defined and measured for a variety of research purposes including medical, sociological, epidemiological, rehabilitative, vocational, and educational studies.

Two major conceptual frameworks of disability are widely accepted (and criticized) within the research community. These are the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) from the World Health Organization (WHO) and the Nagi model (developed by Saad Nagi of Ohio State University). Each model has four distinct concepts or stages. These are disease, impairment, disability, and handicap for the ICIDH model and pathology, impairment, functional limitation, and disability for the Nagi model (IOM). Problems in defining disability are exacerbated, because these concepts or stages (i.e. disability and handicap) are often interchanged.

Functional definitions of disability are commonly accepted measures of disability for the entire population. Broad overall functions fall into socially defined categories, which vary by age, gender, class, and culture. These have been defined by the National Health Interview Survey as: playing (under age 5), attending school (ages 5-17), working or keeping house (ages 18-64), and living independently (for the elderly).

Work disability measures are applied in determining the level of disability among the working-age population. Levels of work disability typically include being completely prevented from working, being limited in the amount or kind of work, and being able to work only occasionally, irregularly, or part-time because of a health condition or impairment.

The activities of daily living (ADLs) and instrumental activities of daily living (IADLs), perhaps the severest forms of disability, measure the ability to live independently. The 6 or 7 standard ADL items are bathing, dressing, eating, toileting (including going to the toilet), getting in or out of a bed or chair (transferring), and sometimes walking. IADLs typically include using the telephone, shopping, preparing meals, doing housework and/or laundry, doing yard work, managing personal finances, and taking medications. ADL measures are limited to persons over the age of 4 and IADLs over the age of 17. IADL measures are only used for adults aged 18 or over.

The presence of ADL limitations (for all but acute conditions) means that some kind of long-term care is needed, because basic activities cannot be performed without help either from another person or from assistive devices (i.e. wheelchair). ADLs and IADLs are critical for programmatic as well as research reasons, because their presence may signal who might be eligible for programs. Among the elderly, ADLs and

IADLs are significant predictors of admission to a nursing home, use of paid home care, use of physician services, insurance coverage, and death. (Weiner 1990)

Other major functional measure of disability include the presence of sensory impairments (seeing, hearing, speaking), the set of WHO functions which measure the functioning capacity of specific body systems (i.e. climbing stairs, working 3 blocks, lifting 10 lbs), and the AMA Committee on Medical Rating of Mental and Physical Impairment of 1958.

Childhood disability measures, particularly for infants and toddlers, are perhaps the hardest to construct. Playing and attending school--usual activities for children--are harder to assess than, say, working for adults. In addition, childhood disabilities can be easily confused with "normal" developmental delays.

Mental or emotional disabilities are also needed in order to fully describe the extent of disability, but functional aspects of mental or emotional conditions/impairments, such as cognitive impairments, senility, mental illness, mental retardation, learning disabilities, are hard to measure and define. No one agreed upon set of "psychological ADLs" exists.

Programmatic definitions of disability are developed with the specific administration of Federal programs in mind. Disability programs are established through legislation, which also often contains program goals, programmatic definitions, and eligibility criteria (Table 1). Eligibility criteria, in turn, frequently consist of functional definitions of disability (i.e. blindness, ADLs). Together, definitions and eligibility criteria in the eligibility process are used to determine who is admitted to programs. Eligibility processes are almost always complex and consist of programmatic definitions (tending to be broad), accompanied by specific eligibility criteria (tending to be narrow).

Depending on the purpose of the program, programmatic definitions can typically include many other factors besides disability. Many of these other factors are themselves hard to define. They include age, income, veterans' status, work experience, and employment.

III. OVERVIEW OF FEDERAL DISABILITY PROGRAMS

Nearly every Department in the Federal government has a program targeted on disability. These disability programs all have unique purposes and offer a wide range of services. These services can be generally categorized into those which: (1) provide include support (cash assistance)--SSDI, SSI, and Black Lung; (2) provide health insurance and direct medical care--Medicare, Medicaid, the DVA Health Services Program, and CHAMPUS for the Handicapped; (3) financed a range of direct supportive services--Administration on Developmental Disabilities program, the Maternal and Child Health Block Grant, and the Alcohol, Drug Abuse, and Mental Health Block Grant, State Grants for Children with Disabilities, State Operated Programs for Handicapped Children, Preschool Grants Program, and Infants and Toddlers with Disabilities Program, and (4) pertain to rehabilitation--Basic Vocational Rehabilitation Service Program.

The Federal government is also involved in funding basic research designed to enable persons with disabilities to lead independent lives. For example, there are programs in NASA, the DVA, and DoD's National Strategic Defense Initiative which adapt defense and space-age technology for rehabilitative uses. In FY 1991, Congress mandated the establishment of the National Center for Medical Rehabilitation Research (NCMRR) within the National Center for Child Health and Human Development at NIH.

IV. SPECIFIC PROGRAM DEFINITIONS AND DESCRIPTIONS

A. ADA

The Americans with Disabilities Act (ADA), a major piece of civil rights legislation signed into law in July 1991, protects the civil rights of persons with disabilities. Equal opportunity provisions for persons with disabilities are contained in the ADA regarding employment, public accommodation, transportation, State and local government services, and telecommunications. Some provisions of the ADA were effective immediately while others will be implemented in the future. As befits civil rights legislation, a broad overall programmatic Federal definition of disability is contained in the ADA. The ADA definition is: "an individual must meet one of the following three tests: (a) have a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (b) have a record of such an impairment; or (c) be regarded as having an impairment. The ADA definition is identical to the one used in Section 504 of the Rehabilitation Act of 1973 and in the Fair Housing Amendments of 1988.

B. SSA Definition

The SSA disability definition, which is used by the Social Security Administration to determine eligibility for both SSDI and SSI, is perhaps the most important and far-reaching programmatic definition. This definition essentially also determines eligibility for Medicare and Medicaid--the two companion health care programs for SSDI and SSI recipients, respectively. Together, these four programs--SSDI, SSI, Medicare, and Medicaid--are the largest Federal programs targeted on persons with disabilities. Thus, the SSA definition accounts for approximately 60% of Federal outlays targeted on nonelderly persons with disabilities. (Burwell, Committee on Ways and Means, 1991)

C. SSDI

The SSDI program provides monthly cash benefits to disabled workers under age 65 and to certain of their dependents. SSDI, enacted in 1956, is the primary social insurance program in the country which protects workers from loss of income due to disability. SSDI is not a means-tested program, but a certain number of insured work-quarters are required. Insured work quarters are those 3-month calendar year quarters

in which an individual works, is covered by Social Security, and earns a specified amount (\$540 per quarter in 1991).¹

Dependent coverage is offered through SSDI to certain disabled persons. Disabled individuals can receive SSDI in three ways: on their own as disabled workers, as widows or widowers of an SSDI beneficiary (if they are aged 50-59), and as adults (aged 18-64) disabled in childhood. This latter group consists of adults disabled before age 22 whose parent(s) are either an SSDI beneficiary, a Social Security retiree, or deceased (but insured under SSA). Typically, these individuals tend to be mentally retarded/developmental disabilities. Provisions for disabled widows/widowers and adults disabled in childhood were intended to provide coverage for those who would be unlikely to ever accrue enough Social Security work quarters to become eligible to retire on their own. The specific programmatic definition of disability for adults disabled in childhood is identical to the one used to determine eligibility for disabled workers. In general, there are different rules for determining disability for the statutorily blind (i.e. those with central visual, acuity of 20/200 or less in the better eye with the use of correcting lens), widows/widowers, and surviving divorced wives--i.e. age, education, and work experience are not considered for disabled widows/widowers. Dependent coverage is also provided to certain non-disabled family members (spouses who are either aged 60 or over or who care for one or more entitled children under age 16). SSDI benefits end at age 65 when a worker retired on disability becomes (for SSA purposes) a worker retired due to old-age. At the end of 1989, 3.6 million disabled Americans received SSDI benefits: 2.9 million workers, 103 thousand widows/widowers, and 586 thousand adults disabled in childhood. The average monthly benefit was \$556 for disabled workers, \$381 for disabled widows/widowers, and \$378 for adults disabled in childhood. (SSA)

D. SSDI Eligibility Process

Under the disability determination process for SSDI, individuals are judged on whether or not they meet the SSA definition. This definition is based on the inability to work:

"The law defines disability as the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months. To meet this definition, you must have a severe impairment, which makes you unable to do your previous work or any other kind of substantial gainful activity which exists in the national economy. To determine you are unable to do any other work, we consider your residual functional capacity and your age, education and work experience."

¹ "Workers aged 31 or over must have a total of at least 20 quarters of coverage during the 40 quarter period ending with the quarter in which the worker became disabled. Workers who are under age 31 must have a total number of quarters equal to half of the calendar quarters which have elapsed since the worker reached age 21, ending with the quarter in which the worker became disabled. A minimum of six quarters is required. Less restrictions apply for blind applicants: only one quarter of coverage for each calendar year after attaining the age of 21 is required." (Committee on Ways and Means, 1991)

Individuals initially file in one of the 1,300 SSA field offices. A 5-month waiting period after the onset of the impairment is required before eligibility. The 5 sequential steps needed to determine disability are:

Step 1: Is the individual engaging in substantial gainful activity (SGA)? The purpose of the first step is to determine if the claimant can work. The level of work is currently set at \$500 per month for disabled and \$810 for blind claimants. No matter how extensive their disability, persons earning more than the SGA are automatically denied SSDI. Information on individuals who pass the first step is forwarded to the State DDS.

Step 2: Does the individual have a severe impairment(s)? The purpose of this second step is to determine if the claimant's impairment(s) is severe and if it is expected to last for at least 12 months or result in death. This determination is made at the State DDS by a team consisting of a disability examiner and a physician. The claimant does not appear before the team. The decision is based on medical and vocational information sent to the team.

Step 3: Are the impairment(s) so severe as to meet or equal the requirements of the medical listing in the regulations? A claimant's medical condition or conditions are compared to the over 100 impairments contained in the SSA Listing of Impairments. These impairments are described as a combination of signs, symptoms, functioning, measurements (i.e. IQ scores), or laboratory findings. Examples of medical impairments which are deemed sufficient to prevent an individual from working at the SGA level include: loss of 2 limbs, fracture of vertebra with cord involvement (substantiated by appropriate sensory and motor loss), IQ of 60-69 and a physical or mental impairment imposing additional significant work-related limitation of functioning, and remaining vision in better eye after best correction of 20/200 or less. (Mather) If the claimant's condition meets or exceeds those in the Listing, then he or she is awarded SSDI benefits, if not, he or she proceeds.

Step 4: Does the individual have any impairment(s) which prevent past relevant work? The DDS team determines at this point whether the claimant can do his or her former job and to determine what (if any) particular types of work on a regular and continuing basis can be done despite the presence of impairments. In order to do this, the claimant's residual functional capacity is assessed. Assessments are made of physical abilities (i.e. strength, walking, standing, lifting, carrying, reaching, handling), mental abilities (i.e. the ability to understand, carry out and remember instructions, and respond appropriately in work settings), and other impairments (i.e. sensory, pain). If the individual's impairments prevent past relevant work, he or she proceeds to the final step. Information about the specific types of functioning needed in the claimant's past job are used to make this assessment.

Step 5: Can the individual do other types of work? Based on the cumulative effects of age, education, and experience the individual is judged by the DDS team on

whether or not he or she can perform work in the national economy. In general, persons under 50 are considered to be able to adapt to new work situations. Education is judged in terms of the number of years of formal training or the ability to communicate in English. For those without formal education, other factors (hobbies, daily activities or testings) are used to determine intellectual capacity. Work experience pertains to those skills learned in the job. Jobs are said to exist in the national economy when there are significant numbers with requirements which meet the specific functional needs of claimants. Isolated jobs which exist in only a few parts of the country outside of where the claimant lives are not regarded as "in the national economy".

Most of those admitted onto SSDI are determined to be eligible, because they meet (59%) or equal (12%) the listings--Step 3. For the remaining 29%, medical and vocational criteria in Steps 4 and 5 are considered. For those denied admittance, 15% did not meet duration requirements (Step 2), 21% did not have severe enough impairments (Step 3), 31% were determined to be able to perform their usual work (Step 4), 26% to do other work (Step 5), and 6% were denied for other reasons. (Mather)

During FY 1990, 39% of the nearly 1.6 million persons who applied for SSDI were initially awarded benefits. About half of the 61% who were denied benefits appealed. In turn, about 27% of those initially denied benefits were later determined to be eligible. Altogether, about 55% of those who initially apply are eventually awarded benefits. (Committee on Ways and Means, 1991)

E. SSI

The SSI program provides monthly cash benefits to low-income aged, blind, and disabled persons. There are no work requirements. Nonelderly persons who apply for SSI must meet both the SSA definition of disability and financial criteria for the SSI means-test. Persons aged 65 or over need only meet the means-test. The SSI program is administered by SSA, but many States also choose to supplement Federal payments.

Unlike SSDI, blind or disabled children can receive SSI. Programmatic definitions of disability differ for adults and children. The adult definition is based on the inability to work. Children are not expected to work, so the notion of comparable severity is used, that is, children's disabilities must be comparable to those of adults. The Supreme Court, in a recent decision (Sullivan vs Zebley) affirmed a Court of Appeals decision which found that SSA erred in using a stricter test for disabled children than for disabled adults who apply for SSI. This decision will increase the number of children on SSI.

Disability determination for adults has two components: a matching of a list of impairments (equivalent to Step 3 of the SSDI eligibility process) and a functional test of the ability of the applicant to engage in SGA (Steps 4 and 5). Children are also matched to a list of impairments, but there is no test comparable to the adult work tests. However, while an assessment of the impact of the impairment on the child's ability to

carry out expected age-related activities was generally carried out, the Court ruled that an individualized functional assessment needed to be done. However, the Court did not identify a method to accomplish this assessment.

Unlike SSDI, when a blind or disabled person SSI recipient attains 65, he or she is still usually considered for program purposes to be blind or disabled. Thus, blind/disabled SSI recipients can be any age. In December 1989, 3.1 million blind or disabled persons received SSI--2.8 million adults and 300 thousand children. The average monthly SSI benefit was \$309 for adults and \$358 for children. (Burwell, SSA)

F. Medicare

Medicare, enacted in 1965, provides health insurance coverage to aged and disabled persons insured under Social Security. There are two ways that persons under age 65 can be eligible for Medicare: (1) by receiving SSDI benefits for at least 24 months (the two year waiting period) or (2) by being in the Early Stage Renal Disease (ESRD) program. Those in the ESRD portion of Medicare must have ESRD and require renal dialysis or a kidney transplant and either be insured themselves through Social Security or be the spouse or dependent child of an insured worker/retiree. There is a 3 month waiting period for ESRD beneficiaries. Nonelderly persons on Medicare who are eligible for SSDI range in age from 20 through 64, while ESRD patients can be any age from infancy onwards. In 1989, 29.9 million aged, 3.2 million disabled persons under age 65, and 58 thousand persons with ESRD were eligible for Medicare. (SSA)

G. Medicaid

Medicaid is a joint Federal-State program which pays for the health care of low-income individuals. Cash assistance from the AFDC program automatically entitles persons to Medicaid coverage, while receipt of SSI usually guarantees Medicaid coverage. There are also a number of optional State programs through which ill or disabled persons can receive Medicaid, but most (79 percent) persons with disabilities are eligible for Medicaid by virtue of SSI.

Medicaid eligibility is very complex and varies from State to State. People with comparable illnesses, disabilities, and incomes can be eligible for Medicaid in one State, but not in another. SSI receipt also guarantees eligibility for Medicaid in most States. However, States may impose additionally more restrictive eligibility criteria for Medicaid than for SSI in the 13 209(b) States of which 3 (Indiana, Missouri, and New Hampshire) employ more restrictive definitions of disability than that used by SSA--the latter 2 exclude children on SSI from Medicaid. In 10 other States (Connecticut, Hawaii, Illinois, Minnesota, Nebraska, North Carolina, North Dakota, Ohio, Oklahoma, and Virginia), States use the same definition of disability, but more restrictive financial criteria than that used by SSI. SSI recipients in these States can become eligible for

Medicaid by incurring certain amounts of medical expenses, that is by "spending down". (Committee on Ways and Means, 1991)

States have a variety of ways in which they can extend Medicaid to disabled persons who do not receive SSI. These include the medically needy programs, optional coverage of noninstitutionalized children, and the Section 2176 Home and Community-Based waiver program.

- Medically Needy programs are present in 35 States, 4 Territories and the District of Columbia. These provisions extend Medicaid coverage to disabled persons who apply for SSI, meet the SSA definition of disability, but whose incomes are slightly above SSI levels.
- Optional coverage of noninstitutionalized children began in 1982. Under this provision, States are allowed to extend Medicaid to all disabled children who live at home, regardless of family income, as long as their disabilities are severe enough to qualify for placement in an institution. As of July 1989, 19 States and the District of Columbia have this provision.
- The Section 2176 Home and Community-Based Care Waiver program has been elected by 41 States. One intent of this program is to keep disabled persons in the community rather than in institutions. Specifically, States can provide home and community-based services not otherwise included in their State Medicaid plans to disabled persons living in the community who would otherwise reside in institutions.

In addition to the SSA definition of disability, State Medicaid programs may use functional criteria for coverage of nursing home services, home health services, personal care services, home and community-based waiver services, and other Medicaid-covered services. Thus, 2 levels of disability criteria may be applied--1 to determine overall Medicaid eligibility and 1 to determine eligibility for specific covered services. The new Medicaid Home and Community care option in OBRA 1990 uses selected ADLs for eligibility, specifically toileting, transferring, and eating. During 1989, about 24.7 million persons received Medicaid of which nearly 3.5 million were disabled. (Burwell)

H. Black Lung

Black Lung benefits are paid to coal miners who are totally disabled as a result of pneumoconiosis (a disease of the lungs caused by the habitual inhalation of irritant mineral or metallic particles), to widows of miners who died from Black Lung disease, and to their dependents. Almost 226 thousand persons were paid Black Lung benefits in 1989. (Burwell, SSA)

I. VA Disability Compensation and Pensions

The Veterans Disability Compensation program, administered by the DVA, provides cash assistance to veterans with service-connected disabilities, that is, they incurred illness or injury while in service. Illness, injury, or disease manifestations must arise during service, but time can elapse. In order to receive benefits, a veteran must first apply to one of 58 regional offices located across the country (one in the Philippines). The application is evaluated by a ratings board, made up of two lay people and a physician. SSDI, SSI, and Black Lung have an "all or nothing disability determination process" wherein a person either is or is not determined to receive benefits. However, a range or band of eligibility exists in the Veterans Disability Compensation program. This range is the ratings system of disabilities. The ratings range from 0 to 100 percent and are based on the presumed drop in income caused by the disability. Employment is not a factor--veterans can be employed and still receive benefits.

The Veterans' Disability Pension programs pays cash benefits to elderly low-income war veterans who have become permanently and totally disabled from non-service-connected causes. This program is similar to SSDI in that there are employability standards. Both of these VA pensions are also available to survivors. In 1989, 2.2 million veterans with service-connected disabilities and 1.2 million without service-connected disabilities received pensions. (Committee on Ways and Means)

J. Veterans' Health Services

The Veterans' Health Services programs, administered by the DVA, consists of a nationwide health care network which provides medical care to eligible veterans. Services must be provided to veterans with a service-connected disability, former POW's, and those with low-incomes. Other veterans are served on a space available basis.

K. CHAMPUS for the Handicapped

The Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) program for the Handicapped is intended to finance services for severely disabled spouses or children of active-duty military personnel after all other sources have been exhausted. The program is small--only 2,500 persons were covered during FY 1987 (Burwell).

L. Social Services Block Grant

Federal funding for social services targeted on persons is provided to States and Territories through the Social Services Block Grant (SSBG) program, which is

administered by the Administration for Children and Families (ACF), DHHS. The SSBG was authorized under Title XX of the Social Security Act, as amended by the Omnibus Budget Reconciliation Act of 1981. Some of these funds can be targeted to people with disabilities. If so, States can use their definitions of disability. Types of services provided include services for children and adults in foster care, services related to the management and maintenance of the home, day care, transportation, employment services, information and referral counseling services, preparation and delivery of meals, and health support services. In FY 1986 States spent \$293 million on the developmentally disabled. (Burwell)

M. Administration on Developmental Disabilities

The goal of the Administration on Developmental Disabilities (ADD) program (in ACF) is to help States assure that their developmentally disabled residents are given the best opportunity through increased independence, productivity, and integration into the community.

Many disabling conditions result in a developmental disability (DD), the most common of which is mental retardation. Other frequent conditions include cerebral palsy, autism, and epilepsy. However, the DD definition is functional not medical and must occur before age 22. In accordance with the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987, a person has a DD if there are substantial functional limitations in at least 3 of the following major life activities (self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency). The 4 ADD program components are: (1) the Basic State Grant program, which provides funds for planning and administrative activities and the development of new programs; (2) the Protection and Advocacy program, which is basically a referral program designed to help people obtain educational, employment, guardianship, transportation, and housing services; (3) the University-Affiliated program, serves to train personnel who will serve the developmentally disabled population; and, (4) the Projects of National Significance Grants, support demonstrations, research, and evaluation projects.

In FY 1986, approximately 57 thousand persons were served through the Basic State Grants programs and 250 thousand professionals, parents, and volunteers were trained through the University-Affiliated program (Burwell).

N. Maternal and Child Health Block Grant--Programs for Children with Special Needs

These programs consist of grants to States. State programs are typically run out of clinics with a mix of medically oriented (i.e. screening and treatment) and social services (case management and counseling). There are no Federal criteria for defining children with special health care needs. These programs primarily served children with

crippling conditions such as polio and cerebral palsy. These programs have expended to serve children with a wide range of chronic health conditions.

Programs for Children with Special Needs are one component of the entire Maternal and Child Health Block Grant program in ACF. In 1980, States spent 20% (amounting to nearly \$99 million) on children with special needs (Burwell).

O. Alcohol, Drug Abuse and Mental Health Services Block Grant

Services are to be targeted to individuals with chronic mental illness, severely mentally disturbed children and adolescents, mentally ill elderly individuals and other identifiable populations which are underserved. There is no Federal definition or requirement as to who can be covered. As with other block grants, States have discretion over who is served. Funds can be used to support community mental health centers and to otherwise support this population.

In FY 1988, \$487 million were allocated by the Federal government for this program. That amount was reallocated among the States in proportion to their population and per capita income.

P. Department of Education's Educational Programs

The Department of Education (Ded) administers 4 educational programs in order to support State efforts in special education and related services for children with disabilities from birth until the age of 21 and the Vocational Rehabilitation program. The evaluation and determination of disability for all educational programs are carried out by a multi-disciplinary team. 3 of the 4 educational programs (all but the Infants and Toddlers with Disabilities Program) use the same definition of disability. In the other 3 programs, the term "children with disabilities" means children (a) with mental retardation, hearing impairments including deafness, speech or language impairments, visual impairments including blindness, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and (b) who, by reason thereof need special education and related services. For ages 3-5 only, the term "children with disabilities" may (at a State's discretion) include children: (a) experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: physical development, cognitive development, communication development, social or emotional development, or adaptive development; and (b) who, by reason thereof need special education and related services.

- State Grants for Children with Disabilities, provide a free appropriate public education to all children aged 3-21 with disabilities. In FY 1991, Federal funding

totaled \$1.85 billion. During the 1986-87 school year, 4.2 million children were served.

- State Operated Programs for Handicapped Children, expand or improve educational services to children with disabilities from birth until 21 currently enrolled in State operated or supported schools. In FY 1991, \$149 million was granted to the States. During the 1986-87 school year, 255 thousand children were served.
- Preschool Grants for Children with Disabilities, provides a free appropriate public education to children with disabilities between the ages of 3 and 5, as well as 2-year olds who will become 3 during the school year. Federal funding for FY 1991 totaled \$293 million. Funds are used to serve and identify these children.
- Infants and Toddlers with Disabilities Program serves children ages birth-2 with disabilities, as well as those who will turn 3 during the school year. The program goal is to improve the provision of early intervention services for these children so that they will less likely to need further special educational services in the future. The term "infants and toddlers with disabilities" means individuals who need early intervention services because they: (a) are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the following areas: cognitive development, physical development, language and speech (communication) development, psychosocial (social or emotional) development, or self-help skills (adaptive development); or (b) have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay. States have the discretion to serve individuals who are risk of having substantial developmental delays if early intervention services are not provided. Each State develops its own working definition of developmental delay. Federal funds in FY 1991 totaled \$117 million.

Q. Basic Vocational Rehabilitation Services

The Basic Vocational Rehabilitation Services program, established in 1920, is one of the oldest disability programs in this country. It is administered through State (or Territorial) VR Agencies by the Rehabilitation Services Administration. The purpose of the program is to help people with disabilities to reach gainful employment. Specific services include counseling and guidance, physical and mental restoration services, and vocational and other training services. In order to qualify, an individual must have the presence of a physical or mental disability which constitutes or results in a substantial handicap to employment and a reasonable expectation that vocational rehabilitation services may benefit the individual in terms of employability. SSDI beneficiaries considered to be good candidates for rehabilitation are routinely referred to State VR Agencies. In FY 1987, \$7.1 million in Federal grants were awarded to State VR agencies, which served 917 thousand people (Burwell).

V. CONCLUSIONS

The huge number of Federal programmatic definitions appears daunting at first, but some definitions fold into each other. The Social Security definition is the most far-reaching as it determines eligibility for 4 major programs--SSDI, SSI, Medicare, and Medicaid. Similarly, the DEd uses basically the same definition for 3 out of 4 education programs.

Programmatic definitions are constructed with the legislative intent of the particular program in mind. The purpose of the legislation is to determine the purpose of the program, who (or which population) will be served, what programmatic definitions will be used, and how duration and severity will be addressed. Specific population groups targeted for disability programs can be divided by factors such as age (i.e. SSDI for working-age adults and children for the DEd's programs), disease (i.e. Black Lung), economic status (i.e. SSI), other characteristics (i.e. veterans status for DVA program), or combinations of these factors. Like disability, many of these population characteristics are also hard to define.

Duration and severity can be defined differently, i.e. the Social Security definition only pertains to so-called permanent disabilities, while the State-run Workers' Compensation programs, recovery is an everyday feature, as recipients can receive benefits for a short time, recover, and return to work. Program eligibility thresholds also vary, i.e. the Social Security definition is an "all or nothing" concept where there are only 2 outcomes--an individual is deemed either eligible or ineligible for benefits. But the Veterans' Disability Compensation program contains degrees (or percentage ratings) of disability depending on severity.

Changes occur in programmatic definitions or even the titles of programs, i.e. the Handicapped Infants and Toddlers Program is now called the Infants and Toddlers with Disabilities Program. Future definitions and eligibility criteria may be based more on the use of ADLs, IADLs, and cognitive impairments. A number of recent Congressional bills propose program eligibility for Federal programs, such as Medicare and Medicaid, on the basis of these factors. These measures were never designed for program eligibility, but their widespread use among researchers and relative ease of understanding has made them appealing. Changes in the underlying more research-oriented concepts of disability definitions and medical criteria are also under consideration (i.e. revision of the ICIDH and the AMA's Guides to the Evaluation of Permanent Impairment). In addition, a PHS Task Force, chaired by the Agency for Health Care Services Research, was recently formed to develop a strategy for a better scientific basis for the determination of disability, particularly for programmatic reasons.

Finally, currently no data or reporting requirements exist either for or in the ADA. However, definitions of disability will play a major role in order to derive the prevalence rates and evaluation data that will almost certainly be required to evaluate employment and other provisions of the ADA.

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TABLE 1: Major Federally Financed Disability Programs	
A. Income Support Programs	
Department of Health and Human Services	Social Security Disability Insurance (SSDI) Supplemental Security Income (SSI) Black Lung program (jointly with the Department of Labor)
Department of Veterans' Affairs	Disability Compensation Program Disability Pension Program
B. Health Insurance Program	
Department of Health and Human Services	Medicare Medicaid
Department of Veterans' Affairs	Health services programs
Department of Defense	CHAMPUS for the Handicapped
C. Supportive Services Programs	
Department of Health and Human Services	Social Services Block Grant Administration on Developmental Disabilities program Maternal and Child Health Block Grant Alcohol, Drug Abuse, and Mental Health Block Grant
Department of Education	State Grants for Children with Disabilities State Operated Programs for Handicapped Children Preschool Grants Program Infants and Toddlers with Disabilities Program
D. Rehabilitation Programs	
Department of Education	Basic Vocational Rehabilitation Service Program

TABLE 2: Definitions of Disability

FEDERAL CIVIL RIGHTS LEGISLATION
Americans with Disabilities Act (ADA): An individual must meet one of the following three tests: (a) have a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (b) have a record of such an impairment; or (c) be regarded as having an impairment. (Same as Section 504 of the Rehabilitation Act of 1973 and the Fair Housing Amendments of 1988.)
DEPARTMENT OF HEALTH AND HUMAN SERVICES
Social Security Disability Insurance (SSDI): An individual must have an inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months. To meet this definition, an individual's impairment or combination of impairments must be so severe that he or she is unable to do past work, but cannot, considering age, education, and work experience, engage in any other kind of substantial gainful activity which exists in the national economy. SSDI benefits are also paid to dependents (age 18-64) of retired, deceased or disabled workers provided they were disabled in childhood, and widows/widowers aged 50 or over who were married to SSDI beneficiaries. There are different rules for determining disability for those who are statutorily blind (i.e. with central visual, acuity of 20/200 or less in the better eye with the use of correcting lens), widow/widowers, and surviving divorced wives.
Supplemental Security Income (SSI): Individuals can qualify as disabled or blind. For disability, an individual must have an inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months. For blindness, an individual must be statutorily blind, that is, having central visual, acuity of 20/200 or less in the better eye with the use of correcting lens. <i>Adults:</i> To meet this definition, an individual's impairment or combination of impairments must be so severe that he or she is unable to do past work, but cannot, considering age, education, and work experience, engage in any other kind of substantial gainful activity which exists in the national economy. <i>Children:</i> A child under age 18 will be considered disabled for purposes of eligibility if he suffers from any medically determinable physical or mental impairment of "comparable severity" to that which would make an adult disabled.
Social Services Block Grant: There is no Federal statutory definition. States set their own criteria for determining disability.
Administration on Developmental Disabilities Program: An individual must have a severe, chronic disability which is attributable to a mental and/or physical impairment; is manifested before the person attains age 22, is likely to continue indefinitely; reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are of a lifelong or extended duration and are individually planned and coordinated; and results in substantial functional limitations in three or more of the following areas of major life activities: (1) self care; (2) receptive and expressive language; (3) learning; (4) mobility; (5) self-direction; (6) capacity for independent living.
Maternal and Child Health Block Grant--Programs for Children with Special Needs: There are no Federal criteria for defining children with special health care needs. These programs primarily served children with crippling conditions such as polio and cerebral palsy. However, these programs have expended to serve children with a wide range of chronic health conditions.
Alcohol, Drug Abuse and Mental Health Services Block Grant: There are no Federal requirements. States have discretion over who is served. However, services are to be targeted to individuals with chronic mental illness, severely mentally disturbed children and adolescents, mentally ill elderly individuals and other identifiable populations which are underserved.
Medicare: An individual under age 65 who received SSDI benefits for 24 months or more or who was medically determined to have end-stage renal disease (that stage of kidney impairment that appears irreversible and permanent and requires a regular course of dialysis or kidney transplantation to maintain life).

TABLE 2 (continued)

Medicaid: A disabled individual must receive SSI in most States. Thirteen States use the 209(b) program option. They may impose additionally more restrictive eligibility criteria for Medicaid than for SSI. Three of these (Indiana, Missouri, and New Hampshire) employ more restrictive definitions of disability than that used by SSA and the latter two exclude children on SSI from Medicaid. In ten other States (Connecticut, Hawaii, Illinois, Minnesota, Nebraska, North Carolina, North Dakota, Ohio, Oklahoma, and Virginia), States use the same definition of disability, but more restrictive financial criteria than that used by SSI. In addition, State Medicaid programs may use functional criteria for coverage of nursing home services, home health services, personal care services, home and community-based waiver services, and other Medicaid-covered services. Two levels of disability criteria may be applied--one to determine overall Medicaid eligibility and one to determine eligibility for specific covered services.

DEPARTMENT OF LABOR/DEPARTMENT OF HEALTH AND HUMAN SERVICES

Black Lung (Pneumoconiosis): Pneumoconiosis is a disease of the lungs caused by the habitual inhalation of irritant mineral or metallic particles. A miner must meet three general conditions: (1) must have (or, if deceased, have had) pneumoconiosis; (2) be totally disabled by the disease (or have been totally disabled at the time of death); and (3) the pneumoconiosis must have arisen out of coal mine employment. Dependent coverage is also provided to widows of miners who died of Black Lung disease and to their dependents.

DEPARTMENT OF VETERANS' AFFAIRS

Veterans' Disability Compensation Program: An individual must have a partial or total impairment by injury or disease incurred or aggravated during military service. A Veterans' Affairs (VA) rating board employs criteria developed by the VA to rate the extent of a disability.

Veterans' Disability Pension Program: An individual must have an injury or disease sustained outside of military service regarding a veteran permanently and totally impaired. Impairment is determined based on the veteran's ability to function at work and at home.

Veterans' Health Services Programs: Veterans' Affairs (VA) hospitals are required to provide care to Class A veterans defined as those: rated as "service-connected; retired from active duty for a disability incurred or aggravated while in military service; in receipt of a VA pension; eligible for Medicaid; a former POW; in need of care for a condition that is possibly related to exposure to dioxin or other toxic substance; in need of care for a condition possibly related to exposure to radiation from nuclear tests or in the American occupation of Japan; or has an income below \$16,466 with no dependents; or \$19,759 with one dependent (with \$1,055 added for each additional dependent). VA hospitals provide care on a space-available basis to persons in Category B veterans, those whose disabilities are not service-connected and have incomes above \$16,466 but below \$21,954. (Category C veterans have higher incomes and must pay a copayment.)

DEPARTMENT OF DEFENSE

Civilian Health and Medical Program of the Uniformed Services (CHAMPUS)--Program for the Handicapped (PFTH): Disability for military dependents is based on the strength and duration of a physical or mental handicap. The physical handicap must be of such severity as to preclude the individual from performing basic activities of daily living at a level expected of unimpaired individuals of the same age group and must be expected to result in death or to have lasted or be expected to last for at least 12 months. For a mental handicap, the applicant must be medically determined to be moderately or severely retarded.

TABLE 2 (continued)

DEPARTMENT OF EDUCATION
<p>State Grants for Children with Disabilities: The term "children with disabilities" means children (aged 3-21): (a) with mental retardation, hearing impairments including deafness, speech or language impairments, visual impairments including blindness, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and, (b) who, by reason thereof need special education and related services. For ages 3-5 only, the term "children with disabilities" may (at a State's discretion) include children: (a) experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: physical development, cognitive development, communication development, social or emotional development, or adaptive development; and (b) who, by reason thereof need special education and related services. Evaluations are carried out by a multi-disciplinary team.</p>
<p>State Operated Programs for Handicapped Children: The term "children with disabilities" means children (birth-21): (a) with mental retardation, hearing impairments including deafness, speech or language impairments, visual impairments including blindness, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and, (b) who, by reason thereof need special education and related services. For ages 3-5 only, the term "children with disabilities" may (at State discretion) include children: (a) experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: physical development, cognitive development, communication development, social or emotional development, or adaptive development; and (b) who, by reason thereof need special education and related services. Evaluations are carried out by a multi-disciplinary team.</p>
<p>Preschool Grants for Children with Disabilities: Children with disabilities between the ages of 3 and 5 are served, as well as 2-year olds who will become 3 during the school year. The term "children with disabilities" means children (birth-21): (a) with mental retardation, hearing impairments including deafness, speech or language impairments, visual impairments including blindness, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and (b) who, by reason thereof need special education and related services. For ages 3-5 only, the term "children with disabilities" may (at a State's discretion) include children: (a) experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: physical development, cognitive development, communication development, social or emotional development, or adaptive development; and (b) who, by reason thereof need special education and related services. Evaluations are carried out by a multi-disciplinary team.</p>
<p>Infants and Toddlers with Disabilities Program: Children from birth until the age of 2 are served, as well as children who turn 3 during the school year. The term "infants and toddlers with disabilities" means individuals who need early intervention services because they: (a) are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the following areas: cognitive development, physical development, language and speech (communication) development, psychosocial (social and emotional) development, or self-help skills (adaptive development); or (b) have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay. In addition, States have the discretion to serve individuals who are at risk of having substantial developmental delays if early intervention services are not provided. Each State develops its own working definition of developmental delay.</p>
<p>Basic Vocational Rehabilitation Services: An individual must have the presence of a physical or mental disability which constitutes or results in a substantial handicap to employment and a reasonable expectation that vocational rehabilitation services may benefit the individual in terms of employability.</p>