

Online Appendices

Supplement to the National Council on Disability Report:

The State of 21st Century Financial Incentives for Americans with Disabilities

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Item 1: APPENDIX A: Six Major Life Domains Affected by Financial Incentives: Education, Employment, Health Care And Long-Term Services And Supports, Transportation, Income Maintenance And Asset Building, And Housing

Many major federal programs that target eligible beneficiaries, such as programs administered under the auspices of the Social Security Administration (SSA), the Departments of Education (Education), Transportation (DOT), Health and Human Services (HHS), Housing and Urban Development (HUD) or carried out by the Internal Revenue Service (IRS), include elements of the three incentive types: direct, indirect, community-based. Nevertheless, by agreeing to forgo undue dispute over program features that split the difference or blur the boundaries, it should be possible to use the predominant features of each program for purposes of categorization.

1A - Education

1A:1 – Individuals with Disabilities Education Improvement Act (IDEA)

The main source of federal funding in education of students with disabilities is the Individuals with Disabilities Education Improvement Act of 2004. While subject to the annual federal budget process, expenditures under this program have grown steadily over the years and are expected to continue to do so. How are these expenditures to be categorized?

IDEA is not a statute intended primarily to provide incentives directly to individuals with disabilities, although local educational agencies (LEAs) utilize federal special education funds in conjunction with local resources to purchase goods and services for students based on Individualized Education Programs (IEPs). The purchases often include assistive technology (AT) or other devices given to students with disabilities for use in school and in connection with school. In addition, the levels of federal special education funding for particular states and districts are determined largely from child-find and counts of students receiving special education and related services. In its overwhelming design and function, IDEA provides resources to school systems to enable them to identify and meet the needs of eligible children and school-age youth with disabilities.

Perhaps the closest that IDEA comes to providing incentives directly to individuals is in two areas: in its recognition of the central role of individualized service-planning through the IEP, and in the authorization of attorney fees to parents who successfully litigate against school system placement or service decisions. Yet neither role constitutes a direct financial incentive to students with disabilities.

It also is arguable that in authorizing the payment from public funds of certain special education costs on behalf of students attending non-public schools, IDEA provides a direct incentive to those students and their families. The incentive here consists in the degree to which the costs for attending private or parochial school are reduced below what they would otherwise have been if the family had been obliged to pay the add-on special education costs itself. If the premise is accepted that public support for such costs does constitute a direct incentive to attendance at non-public schools, then a further distinction must be made between status-based and purpose-based incentives. A status-based incentive, like a non-means-tested half-price mass transit fare to all people with disabilities, is available to anyone who meets the status requirement of having a disability. A purpose-based incentive is one, like the school example just noted, that is available in a particular context to those who make a particular choice, such as attend a private or parochial school rather than a public school.

The rationale for supporting non-public school special education in this way is twofold. First, it is based on an equity argument, and in some instances on a religious freedom argument. Second, it is based on the assumption that in many instances the costs to the public school system of defraying these special education costs will be less than the costs of fully educating and serving the child in the public schools would be. This latter argument has efficacy, though, only if the policymakers or school administrators advancing it actually believe that the subsidy is an incentive to desired behavior. For if the special education payments did not actually increase the likelihood that students receiving the subsidies would choose private over public schools, then what would be the point of giving subsidies?

Another key question surrounding IDEA involves the allocation of federal funds between third party and community-based resources. Public policymakers must decide whether it is necessary to make a distinction between the public school system as a community-based resource or activity, on the one hand, and the consultants, teachers, and other personnel who actually provide services, on the other. Part of the answer to this question may hinge on whether special education funding to the public schools is regarded as a community-based expenditure at all, or whether such expenditures are regarded as expenditures intended to help people with disabilities exclusively. On that debate, far larger than can be addressed here, hinges much of the destiny of public attitudes toward special education in general, and toward mainstreaming in particular.

For present purposes, and in the interests of supporting the policy goals of community integration and full participation that underlie IDEA, in this report NCD adopts the view that special education funds are community-based expenditures. Largely, the funds go to a major public sector institution, are community-based expenditures, made largely on behalf of students with disabilities, and as such fall within Category 3 (community-based financial incentives) of the NCD topology. Except in those cases where the status of individual service providers as independent contractors makes a critical difference to the nature or cost of services provided, or except where any sort of personnel costs raise issues that require in-depth consideration, there is little basis for separating these out as Category 2 items (indirect financial incentives). Nothing in the wording of the federal law, or indeed in the structure of relevant line items in the federal budget, would warrant such further distinctions.

Another area in which IDEA contemplates subsidies to individuals, albeit dispensed through community-based institutions, is in the area of personnel preparation. To the extent that IDEA appropriations may be available or used to help defray the tuition or other costs of people acquiring postgraduate credentials in special education–related disciplines, such funds properly can be regarded as intended to benefit individuals. Since the individuals receiving the funds are not the children with disabilities ultimately intended to benefit from the services of those with improved teaching skills, such subsidies are regarded as going to third parties for the benefit of individuals with disabilities.

As the examples show, IDEA provides incentives of all three types (direct, indirect, and community-based). However, IDEA is not the only source of financial incentives for students with disabilities in the educational context.

1A:2 – The ADA and Section 504

Important civil rights laws, including the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act (Section 504) require both public and private educational institutions to take various steps to make their facilities and programs accessible to students and staff with disabilities. These situations present three analytical complexities with respect to financial incentives. First, they involve not the direct expenditure of federal funds, but rather the use of federal law to leverage the expenditure of state, local and private funds. Second, precisely because of this indirect effect, estimation of the sums expended on accessibility is far from easy. Third and finally, to whatever extent such expenditures are counted in the overall assessment, a question arises regarding categorical fit. While one might see such expenditures as institutional or community-based expenses, their very specific nature requires treating ADA and Section 504 compliance-related costs as expenses incurred by third parties for the benefit of individuals with disabilities. Add to this reasoning the fact that the expenses likely would not have been incurred except for federal civil rights law and the consciousness the law engenders.

This problem of defining and accounting for the costs of civil rights compliance and enforcement must in fact be confronted in each of the six domains or subject areas, because various federal civil rights laws apply to all of them. Reiteration of this discussion occurs in cases where identifiable federal funding, for example in the form of technical assistance, is provided to help achieve civil rights goals. IDEA authorizes some federal funds to be used by states in compliance monitoring, but this appears to be of a fairly routine administrative nature.

1A:3 – Tax Incentives

An important source of financial incentives, that suffuses every subject area, is the Internal Revenue Code. Although this report could address the tax law as a separate incentive

category, the relevance consists in the extent to which and the ways in which tax law subsidizes education, transportation, housing, and other life domains. Thus, tax issues will be addressed, as appropriate, within each of the six subject areas used in this study.

As it relates to education, the tax law provides two kinds of incentives. Through the tax-exempt status of private educational institutions, the subsidy is to the people who make tax-deductible charitable contributions to the institutions. There is nothing particular to people with disabilities in this aspect of the law.

Federal tax law also provides purpose-based financial incentives to individuals, including individuals with disabilities, but again, primarily, there is nothing specific to individuals with disabilities in these provisions. There are certain small provisions allowing families to liberate funds intended for higher education or other school costs when the disability of the student prevents the anticipated activity, but such provisions are likely of minimal significance.

Where the tax law does provide important financial incentives to people with disabilities is in its treatment of certain out-of-pocket, non-reimbursed special education costs borne by families. These opportunities arise under the medical expense itemized deduction.

While the law is clear in denying tax deductibility for any educational expense, those special education expenses that can be characterized as medical in nature (ranging from the costs of specialized services aimed at overcoming the effects of a disability, and the add-on costs of accessible transportation vehicles for getting to and from school, to the costs of specialized AT devices necessitated by a disability) do qualify for the medical expense deduction.

The distinctions the law makes, as well as those it winks at, are slippery at best, putting a premium on expert use of language and on close familiarity with the law. These facts combine with the limitations on the number of taxpayers who can itemize at all, and further combine with the limitations on medical expense deductions (which must exceed 7.5 percent of adjusted gross income in order to be allowable). Such factors combine to form a rather rare incentive. It is available only to people with sophisticated tax-planning resources, the resources to expend

money first and wait for reimbursement, and with tax profiles that allow them to make maximum use of their special education expenses. In short, this is an incentive for the people already sophisticated and financially established.

1B – Employment

As indicated above, because of the close relationship and indeed in some cases inseparability, the information presented here is a result of consolidating job training, placement and employment into one subject area. Under the employment domain is information about vocational rehabilitation, Ticket to Work and Work Incentives Improvement Act, One-Stop Centers, the Office of Disability Employment Policy (ODEP), and other work and tax incentives to employment.

1B:1 – Vocational Rehabilitation

By far the largest and most important source of federal incentives for the vocational rehabilitation training and job placement of people with disabilities is the federal-state vocational rehabilitation system (VR). VR is a system that works through designated state agencies—called designated state units (DSUs)—in each state and territory to provide a variety of services to job-seekers with disabilities and to participate in a number of partnerships and collaborations with other entities involved in labor market issues. In addition to the VR programs in states and U.S. territories, American Indian Vocational Rehabilitation Services (AIVRS) programs are funded by the Department of Education. While the culturally relevant AIVRS programs serve only an estimated 10 percent of the federally recognized tribal nations, the AIVRS role as a source of financial incentives is similar to that of the VR programs in states and U.S. territories. Additional information is available about AIVRS challenges, promising practices, and suggested changes to programs for greater impact on the population served. The Rehabilitation Act also includes authorization and funding for independent living services and services to older adults with vision loss. These incentives defray the costs of services provided by others, to benefit the person with a disability, including the peer counseling and other peer services of independent living centers.

Although the VR Program addresses many activities, its largest and most important role likely remains in providing funds for direct case services to individuals. While some funds go to individual consumers under various circumstances (e.g., through experimental programs or as training stipends), the overwhelming majority of case services funds are channeled through the DSUs to a variety of private, other public and nonprofit sector service providers.

Two points are initially important in categorizing these funds. First, the VR system differs from the special education system in that, unlike the school systems that receive IDEA funds, the state agencies that receive VR funding ordinarily do not regard themselves, and are not generally regarded by others, as direct service providers. That being so, it seems appropriate to characterize most VR incentives as paid to third parties for the benefit, through the provision of specified services, of individuals with disabilities.

Properly, some VR funds are allocable to the other categories as well (indirect and community-based). To the extent, for example, that some program funds may be used to subsidize long-term placements in extended employment (sheltered workshops, in common parlance), these would constitute direct incentives to individuals, but purpose-based incentives in that they are only available to individuals who are deemed eligible to and who opt to work in these settings.

Generally, speaking with respect to the panoply of case services funding administered and provided through VR, the role of consumer-control is a theme of continuing controversy. A most notable example is the requirement for mutually-agreed upon individualized plans of employment (IPE) that serve, as IEPs do in education, to set forth almost by contract the services, activities and responsibilities of both parties, in this case the agency and the service recipient. However, to the degree that state agencies largely retain authority to accept or reject an individual's determinations so far as long-term goals and interim measures for obtaining them are concerned, one would not characterize VR as a consumer-controlled or consumer-directed system. The researchers identified no instance (other than some limited experiments) under the VR Program in which funds go directly to individual service-recipients under circumstances that give them any discretion in their use.

In its partnership and technical assistance role, the VR system may be providing resources to various third parties for the benefit of individuals with disabilities. Job analysis and reasonable accommodation services provided to employers would be an example of this. Other forms of broad educational outreach may constitute community-based supports by not being directed toward any previously identifiable individual.

An interesting variation of mainstream VR Title I expenditure is presented with funds used to provide AT devices to job seekers and employed people with disabilities. These funds are not specifically differentiated or line-itemed in federal appropriations, and may represent an incidental component of program expenditures.

1B:2 – The Ticket to Work and Work Incentives Improvement Act (TWWIIA)

The Ticket to Work and Work Incentives Improvement Act (TWWIIA) represents an innovative effort to broaden the range of service-providers able to work with job seekers with disabilities, and to reduce financial disincentives in the health insurance area faced by such individuals when they seek to enter or return to work.

The most innovative thing this law does is create the Ticket, a voucher or authorization that enables individuals with disabilities (Ticket holders) who receive Social Security benefits to obtain services of a designated value from Employment Networks (ENs). These Ticket holders need to be new entrants to the job training and placement field, motivated by the opportunity, through providing services under the Ticket, of receiving federal reimbursement for their services. In fact, in more states, in part because of: 1) the high cost of serving people with significant disabilities, 2) the extraordinary complexity of the program, and 3) for other reasons, many state VR agencies also have emerged as the most likely EN to provide services to Ticket holders under TWWIIA.

The Social Security Administration (SSA) administers TWWIIA through a series of administrative and implementing contractors. The non-Ticket funds paid to these contractors can be regarded as third party payments. The Tickets and the milestone-based payments that

ENs receive for their work contribute to the complexity. Because the Ticket is more a voucher than anything else, redeemable only at the company store, so to speak, it is difficult to view the Ticket as an incentive paid directly to individuals.

The other major financial incentive to employment provided by TWWIIA is the preservation of health insurance under both Medicare and Medicaid for recipients who would otherwise lose such coverage upon going to work. This is a financial incentive for two primary reasons. First, because the continued provision of coverage costs the Federal Government money, and second, because the insurance has a clear monetary value to covered individuals, even if the amount is not precisely knowable, and even though no funds change hands. As such, continued eligibility for Medicare or Medicaid represents tangible, non-cash, financial incentive directly to individuals. It is probably among the most powerful incentives that go into influencing the calculation, assuming any opportunities for work exist, of how to respond to and deal with such opportunities. Incentives that combat disincentives are no less important, perhaps more important, whether they come in cash or in the rearrangement of program rules.

1B:3 – One-Stop Centers

The VR system is a complex combination of stand-alone and collaborative functions. In its collaborative role, the VR system is one component of the overall federal employment system operating under the auspices of the Workforce Investment Act (WIA). Central to the overall WIA scheme are the so-called one-stop centers, designed to centralize and rationalize the often bewildering array of federal jobs programs. Consistent with the nondiscrimination and accessibility provisions of WIA, one-stop centers are required to serve all job seekers, including people with disabilities.

There are undoubtedly expenses, constituting incentives paid from federal funds that go for meeting these civil rights requirements of facilities and program accessibility, including expenses for making electronic and information technology (E&IT) accessible. Although it is widely believed that many centers have failed to comply fully with the mandate of full accessibility, or have taken the view that their core funding should not be used to meet what they regard as specialized expenses for high-cost clientele, these civil rights compliance costs,

as noted in the discussion of education above, are not an immediate concern. What is the concern here are the programmatic components specifically designed to meet the accessibility mandate and to give the one-stops incentives for doing so.

Among these, one of the most interesting is the Disability Program Navigator pilot program (DPN). This program places liaison personnel in one-stop centers to assist their staff in working with service-applicants with disabilities, and in ensuring that such individuals are made aware of and given appropriate referrals to collateral services that may be of relevance. To the degree that the DPN is intended to directly aid both the one-stop-center staff and its service-recipients with disabilities, it is a financial incentive falling within the indirect and community-based, third party classifications.

1B:4 – ODEP

The Department of Labor's Office of Disability Employment Policy (ODEP) serves a limited coordinating function with respect to disability-related issues within the Department of Labor. Additionally, it administers, with what must be regarded as discretionary funds, a number of outreach, education, technical assistance and training programs, the most notable of which probably being National Disability Awareness Month. Also, the employer-educational work of ODEP may be added to that of the Department of Justice's Civil Rights Division and that of the Equal Employment Opportunity Commission (EEOC) in the disability nondiscrimination area. To these may be added certain aspects of the work of the Protection and Advocacy (P&A) system.

Taken together, these programs, which may be regarded as incentives to the employment of people with disabilities, can be described best as community-based resources. Their importance lies in two features. The first is what they accomplish and the means for evaluating what they accomplish (to be addressed in a later phase of this study). The second is that they may represent the types of efforts that enforcement agencies increasingly will prefer to litigate in the civil rights area.

1B:5 – Other Work Incentives

We normally think of SSA as an agency that distributes income-replacement funds. But features of both the Supplementary Security Income (SSI) and Social Security Disability Insurance (SSDI) programs are designed to facilitate employment by recipients of funds under these programs.

The background of the work disincentives problems plaguing this nation's social benefits is beyond the scope of this study as well. The two problems central here are: 1) that benefits are tied both to the ability to work and to the income and resources of recipients, and 2) that eligibility for health insurance is tied to SSI and SSDI Program eligibility.

The way the law tries to avoid these problems is by creating circumstances in which various items of income or types of resources will be excluded from "countability" for eligibility purposes, including for example key eligibility for Medicare or Medicaid. The mechanisms in question include Impairment-Related Work Expenses (IRWE), substantial gainful activity (SGA), plans for achieving self-support (PASS), along with several demonstration and waiver programs, and (although not yet much used for people with disabilities) individual development accounts (IDAs). These exemptions constitute important purpose-based incentives to individuals with disabilities.

1B:6 – Tax Incentives to Employment

The tax system includes all three kinds of incentives to employment of people with disabilities. By way of direct incentives to individuals, there are the Impairment-Related Work Expenses (IRWE) deduction and the extremely important Earned Income Tax Credit (EITC). The IRWE is an itemized deduction that allows individuals with disabilities to deduct a number of disability-related expenses incurred in order to work. Once again though, its obscurity, together with its status as an itemized deduction, probably limits its usefulness for most people with disabilities. This limitation is particularly egregious when it is recognized that the times at which people will most need to incur large disability-related expenses, such as for the costs of additional training or costs for AT, are likely to be times when people have the smallest income against which to absorb the value of this deduction.

As for the EITC, it is of course a broadly applicable and very important provision for all low-income workers, particularly people with children. It has one provision that makes it of specific applicability to people with disabilities, however. Whereas the coverage of children is limited to those who are young (under 19 or under age 24 and a full-time student), in the case of children with serious disabilities whose parents remain their primary caretakers, the upper age limit is waived. Parents may thus continue to take these children into account for purposes of determining their eligibility for, and the amount of, the EITC.

Provisions of the Internal Revenue Code (IRC) that provide incentives to third parties for the training or employment of individuals with disabilities include the Disabled Access Credit (DAC) and the architectural and transportation barriers removal deduction. While tax aficionados generally have thought of these two provisions as having their greatest impact in the area of public accommodations, both are available for use in defraying the costs of barrier removal and reasonable accommodation as well.

For small businesses, as defined under the law, the Disabled Access Credit provides a 50 percent tax credit of up to \$10,000 per year in “eligible access expenditures,” including readers, sign-language interpreters, or the purchase or modification of equipment. The architectural and transportation barriers removal deduction allows businesses of any size a deduction of up to \$15,000 a year for the removal, according to specified design guidelines, of access barriers to people with disabilities and elders.

One may ask how these provisions act as incentives to the employment of people with disabilities. After all, although they may help offset any add-on costs associated with hiring employees with disabilities, would not such costs be tax deductible anyway, just as any other legitimate business expenses would be? What makes these into specific incentives is that they enhance and accelerate the value of the tax deduction. The expenses covered by the DAC normally would qualify as ordinary deductions. By converting them to a credit, they become worth more to the business. Related provisions also offer flexibility regarding when they can be claimed. The expenses covered by the architectural and transportation barriers removal

deduction normally would be characterized as capital expenses, meaning they would have to be allocated over a number of years equal to the useful life of the renovation or property. By re-characterizing them as an itemized deduction, they can be claimed in the year the expenses were incurred.

Finally, there are a number of tax provisions that, though not directly targeting or specifically impacting people with disabilities, have the potential with minor changes to be of great incentive value to the employment of such people as members of a broader community. The provisions in question are the Low-Income Housing Tax Credit and New Markets Tax Credit Program.

We need to recognize the role that accessible and affordable housing, in itself and as it interacts with accessible transportation, plays in employment. While the details of the changes that would be needed are beyond the scope of this paper, the tax provisions are noted to highlight the complex web of infrastructural underpinnings that underlie the employment destiny of given individuals.

In-depth attention to a variety of other broad-based job-development efforts is warranted to identify simple and inexpensive measures that would make them more responsive to the aspirations of people with disabilities. A convergence of anti-poverty and disability-based efforts is required for this to take place.

1C – Transportation

Interaction between transportation and employment, and bearing in mind the close, if often ignored, connection between transportation and housing, health care and other pathways to community living, are complex. The ADA's transportation requirements have multiple components. Although some public transit agencies had already provided accessible bus service because of political pressure and prior mandates, the ADA greatly accelerated this trend. For example, in 1989, before passage of the ADA, 36 percent of the national bus fleet was accessible. By 2002, 13 years later, 91 percent of public transit buses were ADA lift or

ramp equipped. Improvements of this type are attributed to general agreement that public transit bus use by people with disabilities has increased with the service improvements.¹

The principal point of note about transportation in America, evident throughout the culture and reflected in the allocation of public funds, is that the private automobile is the transportation modality of choice for most Americans. More important though, the design of the environment has contributed to this preference by making many trips difficult or impossible to complete by any other means. Even when public or mass transit is available, scheduling, routing, financing, capital investment, crowding and other factors, including inaccessibility, all may contribute to reducing its value for those people who would choose to utilize mass transit.

So many sources of public funding converge to support the automobile society and culture that it would be impossible to list them all. They range from a number of indirect subsidies to keep down the cost of gasoline, to excise tax exemptions for trucks and light trucks (including SUVs), to tax credits for hybrid vehicles (apparently intended to compensate for the tax exemptions accorded to large SUVs), to vast federal expenditures for highway building and road maintenance, to literally dozens of others of a direct and indirect nature.

For people with disabilities, therefore, the question is twofold: Does the emphasis on private automobile use affect relative freedom of movement differently than it does that of other people, and do the funding streams incorporate provisions that are designed to recognize or respond to any of these needs?

There are people whose disabilities make traveling by means other than private automobile difficult and stressful, without regard to legal dimensions of accessibility. For them, the existence of the car culture and the fact that most locations are now designed to accommodate the automobile is likely a net advantage. On the other hand, for many people the inability to drive or even to afford an automobile is itself a serious social disability. Against this backdrop, let us look at various programs.

1C:1 – Automobile-Oriented Funding

Considerable publicity during the summer of 2005 was directed to the federal highway legislation adopted by Congress after two years of gridlock. Whether the numerous, earmarked projects it authorized and funded are valuable contributions to the transportation infrastructure or other special expenditures, the question is whether the bill contained any specific earmarks of importance to people with disabilities. Pending a more thorough review of the lengthy enactment than has thus far been possible, initial indications are that if any of the earmarked projects were of special significance for people with disabilities, this was incidental.

With regard to the broader provisions governing the use of highway funds under the law, there are a number of provisions that can be regarded as intended to enhance the transportation access of people with disabilities. To the extent that these provisions, though intended to recognize and benefit particular subpopulations, involve the imposition of requirements on the way states and municipalities spend their highway money, these provisions can be regarded as examples of infrastructural expenses targeted to people with disabilities.

Provisions in question would include funds appropriated for specialized and experimental transportation programs for underserved areas and groups; provisions regarding accessible paths of travel in certain contexts; and (in conjunction with the Telecommunications Act) requirements for the compatibility of emergency roadside phones with the 911 emergency system, to name a few.

The dollar value and net effect of these and related expenditures and requirements is not known and likely difficult to determine. It may be that the mechanisms involved are as important as the dollars expended, or perhaps more so. At issue here is the connection between regulation and funding. In subject areas like transportation, housing and health care, analysis of the nature and role of financial incentives requires careful assessment of the leverage value of regulations that guide the expenditure of funds. Regulations have been subjected to various kinds of cost-benefit analysis over the years. Their leverage value in influencing the expenditure of funds, when the funds were not appropriated with specific reference to the goals of the regulation but are subject to the regulation nonetheless, must be

an important area of study in the development of sophisticated cost-benefit measurement tools.

The leverage value of pro-accessibility or disability-oriented funding categories, regulations, set-asides or similar mechanisms is heightened where matching state funds are involved. Federal regulations not only condition and direct the expenditure of federal funds, but where programs include matching fund requirements, or where federal funds provide seed money for state-based efforts, regulations help leverage the use of these funds as well. Discussion of this matter is at greater length in the civil rights section, below.

1C:2 – Fixed Route Public Transit

1C:2A. Intercity

1C:2A(i) Air Transport

The Air Carrier Access Act of 1986 (ACAA) imposes nondiscrimination and accommodation requirements on most commercial airlines operating in the United States. ACAA is an example, albeit a small one, of the kind of leverage mentioned above, because while in this case no federal funds are appropriated to implement ACAA (though some funds are used to support its enforcement by the Department of Transportation (DOT)), airlines are obliged to spend some money to comply with the law.

Where federal funds come into the mix, again more interesting for the concept than for the amount, is in the exercise of the DOT authority to fine carriers for violation of the law. DOT has imposed several fines on carriers. If it is accepted that these fines become federal money when collected, it is interesting to note that the government has routinely remitted them, provided the sums are used for ACAA-related activities such as employee training in disability awareness.

To the degree that the ADA requires municipal airport authorities to make certain expenditures for accessibility and accommodations, it, too, may be said to be an indirect source of disability-

specific infrastructure funding. This role is far more pronounced in the rail and bus transportation area.

Another variable in the air transport context brings us face to face with the subject of user fees. The Transportation Security Administration (TSA) has embarked on a number of disability-related initiatives. Activities of TSA, as well as other airport infrastructure, are funded partly from per-ticket fees, which are in effect excise taxes paid by air travelers. To the extent that any of these fees go to defraying access-related costs, they too can be considered, however unexpectedly, a form of federal financial support.

1C:2A(ii) Rail Transportation

Title II of the ADA is very much concerned with rail and bus transportation. There are a number of specific timeframes in the law applicable to the rolling-stock and station facilities of each. Amtrak, the nation's passenger rail service, receives direct federal support, both for capital and operational expenses. As such, although neither the precise sums in question nor the specificity of appropriations language has yet been reviewed, it is clear that federal financial support to a third party (namely, Amtrak) does go toward making intercity rail travel more accessible.

A question suggested by the interaction of regulations and funding must be addressed by the research. Can one properly speak of financial incentives where the disability-oriented expenditure is mandated and where failure to make such expenditure could put other funds at risk? For purposes of this report, the semantic liberty is taken of using the term incentives broadly, to include all identifiable expenditures that meet any of the financial incentives study criteria for disability relatedness.

No data have been located concerning the amount that accessibility measures cost the National Passenger Railroad Corporation, or what percentage of such costs is covered by federal funds. Likewise, data on the impact of such expenditures have not come to light. Were such data to exist, it would have to be explained by the exploration of two questions in order to

be fully meaningful. It would have to address the question of how many people with disabilities are motivated or enabled to use rail service that otherwise could or would not. In addition, it must ask what costs of relevance to federal policy or funding would have been incurred as a result of the inability or disinclination of such people to utilize rail service.

1C:2A(iii) Inner City Buses

Title II of the ADA, together with Safe, Accountable, Flexible, Efficient Transportation Equity Act: A Legacy for Users (SAFETEA-LU), includes clear and specific requirements for the accessibility of inner city buses and in some cases for the procedures that must be used to ensure that access is effective. There is significant public subsidization of bus travel, emanating from numerous sources (including local funds, bond issues and direct expenditures or tax forgiveness for the building or maintenance of transportation terminals), which helps to account in many cases for the price advantage held by bus over rail on various competitive routes.

Whether regulation and funding are commensurate with one another, or put another way, whether federal funds pay for federally-imposed requirements, is a key question that should be considered. Alternatively, subject to insurmountable complications under currently existing accounting practices, is the question of whether other forms of public subsidization offset the costs of mandated accessibility, and whether, paradoxically, the costs of accessibility, however met, yield increases in revenue through more ridership that have a significant bearing upon the cost-benefit assessment.

1C:2B. Fixed Route Public Mass Transit

Depending on the city and region, public mass transit, including local buses, light rail, subways and commuter trains, play an important role in the morning and afternoon traffic reports that are a staple of almost every radio station and television newscast in the country. Robust mass transit is deemed important to the economic development of many metropolitan areas, but it also is important in the daily lives of individuals.

So important has mass transit become in the lives of people, particularly older people who lose the ability or confidence to drive, that certain urban areas like New York City, with dense mass transit webs, have been dubbed NORCs (naturally occurring retirement communities). Of many people with disabilities of any age who cannot drive (or who cannot afford the add-on costs of vehicle accessibility) this is no less urgent an issue. The question then becomes: Do current financial incentives and support for mass transit recognize and respond to the identifiable and specific concerns of customers with disabilities?

In the area of capital funds for equipment, federal funds are contemplated for use in meeting vehicle and station accessibility requirements. Once again, reflecting the interplay between regulations and appropriations, this occurs both in terms of the direct expenditure of funds and the risk of loss of other funds if requirements are not met or procedures not followed.

Accessibility requirements supported with or leveraged by federal funds would include, for example, the percentages of bus fleets that must be wheelchair equipped, the accessibility to people with vision and physical disabilities of fare machines, and even the accessibility of transit system Web sites. Although these requirements are aimed at passengers with disabilities, they also are examples of universal or accessible design. In this context, they are the sort of amenities that benefit all passengers. For this reason, they represent the classic instance of disability-oriented measures, expenditures or incentives that have as their byproduct a benefit to the entire community. Perhaps, at least in some communities, inversion of the analysis may be appropriate. That is to say, it may be that awareness of the needs of passengers with disabilities or the desire to attract such passengers was an extension of more basic progress in awareness of what constitutes good design.

In contrast to other incentives, useful data may be available about some of the consequences of accessible mass transit. Indeed, it is believed that the willingness of transit system owners/providers to take such measures as equipping new buses with wheelchair lifts may have arisen in some cases from calculations that the increased capital costs associated with such accessibility would be offset by savings in the paratransit program. Apart from the benefit of such savings, further evidence of savings and community integration could, without much

difficulty or cost, be gathered through the use of already commonly used research techniques. Transit systems routinely survey riders to determine their needs and attitudes. It would be relatively straightforward to use standard research techniques, involving the surveying of voluntarily self-disclosing passengers with disabilities, to ascertain the extent to which system accessibility has increased their utilization of transit. Considerations of the quality of their experience and the impact of greater access to other spheres of life also could be addressed.

1C:3 – Paratransit

Perhaps the greatest change in the nation's transportation system over the past generation has been the development of paratransit as a supplement or replacement for fixed-route transit for people whose disabilities make the general system unusable, despite its accessible design. Paratransit, as operated by local or municipal transportation agencies, represents one of the closest approaches to a direct transportation subsidy to individuals. The other near approximation to direct incentives to individuals is the reduced fares required by federal law to be provided to passengers with disabilities by municipal transit systems. Neither paratransit nor reduced fare is means-tested. Both are status based, in that the recipient of the service or discount must be an individual with a disability (or in the case of the fare subsidy an individual over the age of 65), but legal status alone is not sufficient to make one eligible for paratransit services.

Eligibility for paratransit is determined on an individualized, case-by-case basis. Beyond even individualized eligibility determinations, there is a further concept, disliked by many, but legal, called trip eligibility. With trip eligibility people with disabilities, though eligible in principle, are granted or denied the service for particular trips or types of trips based on purpose of trip, destination, or other factors.

Critics have maintained that disproportionately large amounts of paratransit resources have been dedicated to reviewing front-end eligibility screening rather than to delivering the service. Whether this is true or not, it presents an opportunity for asking how the character and implications of administrative expenses should be handled. As a general matter, the cost effectiveness of elaborate procedures for screening out ineligible recipients, in paratransit or

other programs, largely has been exempt from outcome measurement. Simply stated, the existence of finite limitations on the resources available for any program, coupled with the desire to avoid furnishing of services to ineligible individuals, have led to a relatively unquestioned acceptance of the notion that sums spent on ensuring program integrity and focus are well spent. Rarely has this assumption been put to the test, especially in programs for people with disabilities.

There is in fact room for disagreement over the primary characterization of paratransit. Except in cases in which taxi vouchers are used, neither funds nor scrip come into the hands of the riders. Moreover, because the vouchers can be redeemed only for one service, even if the recipient sometimes has choice over the selection of the provider, it would be hard to regard such a voucher as an individual subsidy. More precisely, the paratransit system can be seen as a tightly targeted incentive, available to transit agencies, to underwrite certain capital and operational costs associated with the provision of door-to-door service to individuals who have what are deemed transportation disabilities.

1C:4 – New Freedom Initiative

The President's broad-based commitment to expanding the opportunities for and facilitating the integration of people with disabilities into all phases of community life is embodied in the New Freedom Initiative (NFI). Through the NFI a number of experimental and demonstration projects aimed at extending transportation services through innovative programs, using traditional and nontraditional providers, have been undertaken. These experiments vary in nature, and it is not the purpose to describe them in detail here. What matters is that thus far these projects have not generated a sufficient body of data to bring about any fundamental changes in the character of local and regional transportation services in this country.

Even if standardized data collection and outcome criteria were used to ensure the collection of comparable data and to facilitate comparison among experimental approaches, a question remains regarding how and whether the results of the NFI transportation projects, under the Real Choice Systems Change Grants, for example, are being aggregated, disseminated and compared. Put another way, the question emerges whether the full value of these experiments

is being harvested. Cumulative data must be aggregated and synthesized to generate broad-based conclusions.

1D – Health Care and Long-Term Services and Supports

Both direct and indirect financial incentives are involved in the provision of health care, medical services and insurance coverage to people with disabilities. The incentives also are among the three categories of incentive recipients: individuals with disabilities, third parties and community-based resources.

1D:1 – Private Health Insurance

The most important health issue for most people is health insurance. Although government-funded programs, including most notably Medicare and Medicaid (both discussed below), are steadily growing in importance as sources of health insurance and care, private insurance remains the source of coverage for most employed Americans. As important, almost all proposals for health system reform make extensive use of the private insurance sector—some through managed care contracting with the government, and some giving them a far greater role.

Although many people regard the effort as inadequate, judging from the lack of affordability and unavailability of insurance for many people, and although an estimated 45 million Americans are uninsured, in addition to an indeterminate number who are underinsured, the government provides financial support for the purchase and provision of private sector health insurance through a number of mechanisms. One question, after describing the principal ones, will be: Do those mechanisms respond to the unique insurance coverage issues facing people with disabilities?

The means by which the government subsidizes health insurance can be summarized briefly. These means are concentrated in the area of employer-sponsored insurance. They include, among other modalities: tax deductibility to employers of premiums paid for employee health insurance and tax exclusion of the value of such premiums from the wages of employees;

negotiation of private sector contracts that include fringe benefits for project staff health insurance in many instances; health savings accounts (that allow tax deferral and potential tax exemption of sums set aside for meeting co-payments under high-deductible policies); and direct subsidization under the Medicare Modernization Act of employer-sponsored retiree health and drug coverage (on the theory that this will be less costly to the public than would the abandonment by companies of these plans).

In the area of individually-purchased coverage, financial incentives are less systematic, but they do exist. One that is particularly controversial is the exemption of the insurance industry, including the health insurance industry, from a number of legal requirements applicable to other industries. In exempting the insurance industry, to varying degrees, from civil rights laws, antitrust laws and generally applicable accounting practice (GAAP) requirements, the argument has been made that such exemptions allow the industry to extend coverage to more people and at lower costs. Arguments in favor of genetic anti-discrimination legislation currently pending in Congress largely are predicated on the contention that such legislation, however desirable in principle, would drive up the costs and hence reduce the coverage available to Americans.

If the opponents of such regulation are consistent in their analysis, then it follows that the government's forbearance to subject the industry to certain regulations constitutes an indirect financial subsidy.

Although not within the scope of this study, owing largely to their variety, state funds play an important role in the availability of private health insurance. Modalities include high-risk pools, purchasing groups, regulation of premiums (for individual policies), and, in parallel with the Federal Government's role in guaranteeing the solvency of employer-based plans, maintenance of oversight of the financial stability of insurers operating in the state.

Against this brief backdrop, the major question for us is whether the federal efforts take into account people with disabilities and, indeed, what the issues are that such awareness should include. It generally is believed that lack of access to private sector insurance, whether through

literal denial or through lack of affordability, is a major cause for the persistence of high unemployment rates among people with disabilities who cannot risk the loss of Medicare or Medicaid coverage that they fear would ensue from their entry into employment. To a remarkable degree, disability-based discrimination is overt and legal. Under a provision of the ADA, for example, activities of insurers are explicitly excluded from the law's coverage if they involve underwriting or classification of risk. Despite the lapse of years since adoption of the ADA, no authoritative court decisions have been forthcoming regarding the burden of proof under this provision. It appears that the mere assertion by an insurer that its refusal to grant coverage to an individual, based on its assessment of risk, will begin an inquiry into whether that assessment was based on data or indeed on any rational considerations, or if it was solely the expression of stereotype and myth.

In the employer-sponsored health insurance setting, governed by the Employee Retirement Income Security Act (ERISA), opportunities for the denial of coverage are somewhat limited. However, employer-sponsored discretion to structure the coverage, the benefit levels, the caps and the outright exclusions give rise to numerous opportunities and methods for limiting coverage for people with disabilities who have high, recurrent, or merely unusual expense, such as the costs of AT.

Through research, NCD has been able to identify little in federal law or budgeting that targets private health insurance availability for people with disabilities. This is distinguished from long-term care insurance.

Beyond the question of access to insurance, there is the question of what is covered when coverage is nominally forthcoming. People with disabilities may need specialized services or care, and may need auxiliary aids and services that enable them to participate actively in care planning and monitoring. If the Federal Government were going to respond to any of these needs, by funding, regulation, or both, how might it do so?

It might fast-track U.S. Food and Drug Administration (FDA) review of AT devices (but in fact the current system for device review appears in several ways to have the exact opposite result

with AT devices that come within FDA jurisdiction). The government might facilitate research into disability-related or disability-specific treatments and modalities through CMS, through its relationship with the Blue Cross Blue Shield research arm, or by other means, but so far as can be determined, it does not. The government could articulate nondiscrimination requirements or definitions of medical-necessity for use by insurers that enhance the availability of specialized goods and services. But there is no federal definition of medical necessity. Nor does federal law include any coverage mandates (comparable, say, to mandates at the federal or state level regarding coverage for mammography or of minimal hospital stays for childbirth) that would relate to goods or services of particular value to people with disabilities. Finally, federal law places almost no limits on caps or item exclusions.

ID:2 – Medicare

Medicare is the system of federally-financed medical insurance for people over the age of 65 and people receiving Social Security Disability Insurance (SSDI). Since recipients of SSDI are people with disabilities, and in fact, many recipients over the age of 65 are as well, Medicare properly can be regarded as a program of insurance for people with disabilities.

Although there are some situations in which beneficiaries receive cash reimbursement, these instances are rare, and in any case, such payments would be purpose specific and need to be used to pay for services already received. For the most part though, Medicare represents payments to third parties—hospitals, doctors, short-term skilled nursing facilities, certain home-health-care providers, durable medical equipment (DME) suppliers, and now managed care organizations and pharmaceutical manufacturers—on behalf of beneficiaries.

In terms of eligibility, Medicare for people with disabilities under the age of 65 differs markedly from the program for elders. People over 65 have automatic entitlement to Part A hospital coverage, and are subject to financial penalty if they fail to sign up for Part B and the new Part D as soon as age-eligible. But no requirement of disability and no income limit or means-test applies. By contrast, because of the link with SSDI, people with disabilities under age 65 are eligible for Medicare only if deemed unable to work according to the standards of the Social Security Act.

Beyond the question of Medicare eligibility, there once again is the issue of coverage. To say that Medicare covers some people by virtue of their status as people with disabilities is not to say that it necessarily covers services that would be of particular importance to people with disabilities. In fact, as still a predominantly acute care program, Medicare appears distinctly ill-suited to provide the rehabilitative, AT support services and specialized resources that many people with disabilities need.

Many people fear that the enormous sums required to fund the new Medicare Part D prescription drug benefit will result in cuts in coverage for other services of particular importance to people with disabilities. Recent moves by CMS, apparently dictated by cost, to curtail the scope of powered wheelchairs and other mobility aids are particularly ominous in this regard, since such devices are disproportionately and uniquely needed by beneficiaries with disabilities.

ID:3 – Medicaid

Operated with federal and matching state funds, and implemented by the states, Medicaid is the federal-state system of health insurance for people who are poor and who in addition meet one of two other conditions: either they are people who are blind or have disabilities, or are people over the age of 65. Other categories have been added, including people whose earnings exceed normal maximums but who are allowed to receive or retain coverage under state buy-in programs and people covered under waiver programs.

Given Medicaid's significant focus on people with disabilities, attention once again shifts from the question of eligibility to that of the scope of coverage. Like Medicare, indeed like any health insurance, Medicaid focuses on traditional medical services, goods and practitioners. To do this it distinguishes between mandatory services, which states must provide as a condition for receipt of federal funds under the program, and optional services that states are free to provide or not as they see fit.

In the provision of both mandatory and optional services, states have considerable discretion: some of it inherent in the design of the program, and increasingly much of it derived from authority given them by the Federal Government to waive the applicability of one or another ordinarily applicable requirement.

1D:3A. Third Party Medicaid Incentives

As a financial incentive, Medicaid, by design, affects people with disabilities. It impacts their lives primarily through payments to third parties—to health care practitioners, medical institutions, nursing homes or others—for the provisions of services and care. What is ironic is that although people with disabilities represent a key target population of the program, the specific needs of people with disabilities are not systematically addressed in the range of goods and services required to be provided. To the degree that there may in some cases be an overlap between disability and health problems or medical needs, those disability-related issues that are subsumed under standard medical treatment will be addressed. But when it comes to needs of a specifically disability-related, non-medical nature such as AT, PASS, home modifications, or rehabilitation services (which are in theory covered), the picture is quite different. While a number of these needs could be met by such services as vision and hearing services, orthotics and prosthetics, speech-language pathology, DME or rehabilitation, these low-incidence services fall almost exclusively within the discretionary area, and as such have been among the first casualties of budget cutting and cost-savings efforts at the state level. Moreover, even when they are covered, an enormous range of limitations on which diagnoses will trigger their use, how much or for how long they can be provided, how much they can cost, which practitioners are permitted to prescribe or implement them, which suppliers must be used for procurement, what prior authorization will be requested or what specific devices or kinds of devices can be used will combine to make the provision of disability-related services to Medicaid recipients with disabilities a challenging and uncertain prospect.

For people with disabilities of low income, the availability of insurance coverage through Medicaid is of great significance. Economics, lack of employment and disability itself combine to make private health insurance unavailable or unaffordable to many people with disabilities.

But once again, the fact of coverage and the content of coverage must be taken into account in determining the extent and value of this, or of any other financial incentive.

A dilemma about Medicaid is whether it constitutes a financial incentive to community living. To say that it is a financial incentive provides little information until the question of what is incentivized has been fully illuminated. On balance, it would appear that Medicaid as a financial incentive to community living varies greatly from state to state, depending on targeted populations and the defined scope of services covered by the state plan and federally approved waivers.

When Medicaid was created in 1966 it was not designed as an acute care program in the way that Medicare was designed. Nevertheless, many, if not most, of the concepts (independent living, community integration, deinstitutionalization, home- and community-based services, aging-in-place) that today dominate the Medicaid debate were unknown at the time of its creation. Likewise, many of the services of greatest importance and value for people with disabilities, such as those previously mentioned, were not part of policy and decision makers' consciousness when the program was designed. Perhaps most important in this regard, the ADA did not exist when Medicaid came into existence.

Although opinions differ regarding whether and how this can be modified, it is widely agreed that Medicaid resources disproportionately incentivize facility-based services at the expense of home- and community-based services. Hospital and nursing home services are mandatory; home- and community-based services are covered largely by waiver programs, making them more tenuous than optional services. Beyond this, specific services needed to support a community-based or community-integration model of health care are marginal within the Medicaid framework.

The fit between this venerable statute, on the one hand, and emerging new needs and awareness, on the other, is dramatized nowhere more vividly than in the 1999 Supreme Court's *Olmstead v. L.C.* decision and in its aftermath. The *Olmstead* case held unnecessary institutionalization a violation of the ADA's community integration and least restrictive

environment provisions. The Court provided a three-pronged test for determining when and how nursing home residents should or could be returned to the community.

In the wake of *Olmstead*, the Federal Government, through the NFI and other initiatives, has assisted states in complying with the mandate of the case. Among other things, states have been expected to prepare *Olmstead* implementation plans, which are supposed to reflect progress, measurable goals and procedures for assuring the necessary interagency and service coordination. Opinions differ regarding the success and vitality of these efforts, but it is notable that because they have never been brought under the mandatory funding category of the law, the *Olmstead* implementation services and activities are more exposed to budgetary pressures and more vulnerable to new preoccupations than are traditional hard-core medical services.

1D:3B. Direct Medicaid Incentives

Although Medicaid operates primarily through payments to third party caregivers, a tiny but growing part of Medicaid funding is being directed to individuals and this trend is likely to grow over the coming years. Through a variety of experimental federal programs being launched jointly by CMS and SSA, under such rubrics as cash-and-counseling, life accounts, asset-development and others, and as embodied in legislation such as Money Follows the Person, these initiatives have the related goal of increasing autonomy on the part of beneficiaries. For example, such programs reward beneficiaries for frugality by allowing them to keep a portion of what they save, reducing total program costs, and creating incentives for individuals to save program funds. As a result of these converging initiatives, a small but growing stream of Medicaid funds, potentially including federal funds and leveraged state matches, is likely to go directly to beneficiaries with disabilities. Two key questions will emerge in evaluating these initiatives: How effective are these funds in bringing about sanctioned activities or established goals of the program? How much choice will beneficiaries actually have in the way their individual funds are expended?

From the standpoint of describing incentives, the second question is of more immediate importance. It seems likely that some program-related limitations will be placed on how these

funds can be spent. The likelihood of political opposition to direct payments to recipients already exists, and if they are allowed to retain unspent funds, in derogation from existing rigid means-testing of the program, such opposition is likely to be greater still. Given prevailing and politically potent stereotypes about the reason poor people are poor, the absence of significant limitations on how permissibly the funds are to be spent probably would prevent growth of such programs beyond the isolated-experiment phase. That being so, the Category 1 direct-to-individuals Medicaid incentive will not be open-ended.

What will be critical in this regard, and based on the design of early experiments does seem likely, is that the permissible uses will include disability-related expenses that cannot be met by available payments to third parties. Of course, if funds made available directly to recipients are obtained by being taken away from traditional program funding streams, then it may be that the nature but not the overall level of financial incentives will be changed. With this possibility in mind, it will be useful here to consider how proposals for Medicaid reform and restructuring bear upon the role of incentives for people with disabilities.

1D:3C. Medicaid Program Reform

State governors from both major political parties appear to agree that Medicaid is far too expensive to be sustained at its current rate of growth or under its current structure. Federal level policymakers in the Executive Branch and in Congress likewise appear united in the belief that current and projected rates of program growth are unsustainable, though strong ideological divergences emerge around the reasons this is so or what should be done about it. Proposed solutions take numerous forms, such as greater use of managed care as a means of achieving cost control; imposition of expenditure caps on the states; narrowing of program eligibility criteria; reduction in the scope of covered services; greater use of tax and other incentives to increase the availability of private insurance; and, of course, heard hardly as frequently, adoption of some form of single-payor or national health care which would essentially supersede Medicaid and dramatically broaden the funding base for medical care in this nation.

It is beyond the scope of this research to discuss these proposals in any depth. The point of listing some of them here is to note the startling absence from the debate of any discussion or apparent awareness of the specific issues relating to people with disabilities in the current operation and potential reconfiguration of the Medicaid Program.

With cost-saving emerging as the chief imperative of many Medicaid reform proposals, there is ground for fearing, especially in the absence of awareness of disability-related issues, that cuts will impact people with disabilities disproportionately. This is likely for several reasons, with the most significant being that although there is no necessary correlation between disability and ill health, extremely high-cost recipients are very likely also to be people with disabilities. As such, any cost-cutting measures that focused on reduction of per capita costs, control of high-cost services, elimination of low-incidence services or similar measures would hit financial incentives for the care of people with disabilities harder than those for the care of others. So too would expanded use of managed care, unless accompanied by provisions reflecting awareness that people with disabilities may need specialized goods and services often available only out-of-network or out of their geographical areas, or from nonstandard sources.

1D:4 – Electronic Medicine

One major governmental initiative in the health care area relates to the creation, under authorization of the Health Insurance Portability and Accountability Act of 1996 (HIPPA) of an electronic medical records system over the coming decade. Many considerations, ranging from avoidance of costs to minimization of medical errors, have been cited in support of this initiative. What would make this initiative responsive or unresponsive to the health care needs of people with disabilities?

Broadly speaking, what would make this forthcoming system more effective as an incentive to the provision of health care to people with disabilities, or for that matter for the participation of people with disabilities in the health care system on equal terms as those of people without disabilities? Accessibility in the design of the system, to assure equal access irrespective of disabilities, would be one measure that could help to bring this about. As such, employment would be implicated too, because more jobs in the growing health care system would be

available for people with disabilities. Inclusion in the data sets of categories that are of particular relevance to people with disabilities and that would improve the quality of data on disability also would be of great value in this regard.

1D:5 – Health Care Tax Strategies

In health care as in every other sector, the tax law is coming to play an ever-larger role. The most tangible recent example of its increasing importance is the creation in 2003 of the Health Savings Account (HSA) under which people are encouraged, through tax benefits, to purchase high-deductible health insurance policies. This report discussed this and other ways in which the tax system supports the current insurance system.

Beyond this, there are the medical expenses deductions, including expenses for many AT items that are available to taxpayers who itemize. Lastly, in this regard, there are provisions in the IRC allowing for waiver of the early withdrawal penalty tax when the premature withdrawals are used to meet medical costs.

To the degree that such provisions help offset the economic consequences of catastrophic illness, they undoubtedly represent important and direct financial incentives to at least some people with disabilities. But for those people with disabilities whose specialized needs are of an ongoing nature, not to mention for those who lack retirement savings or who lack income against which to offset their deductions, such provisions are of limited value.

As a general matter, except for definitions of “medical expenses” that include various AT devices, none of the provisions of the Internal Revenue Code that subsidize individually purchased health insurance or care reflect any specific awareness or particular concern to maximize the value of the incentives to people with disabilities or their families.

1D:6 – Health Care Research

1D:6A. Outcomes Measurement and Evaluation

With evidence-based practice the watchword, outcomes and evaluative research have become central to many of the resource allocation and prioritization decisions made by and for the

health care system. But health system outcomes are extremely difficult to measure, even compared to outcomes in other areas.

The complexities encountered in measuring the efficacy of health interventions are well beyond the scope of this study. For present purposes it is enough to note that the government plays a major role in evaluations research, including through its expenditure of funds and through the private expenditure it commands by regulation. From studies conducted at or directly funded by National Institutes of Health or the Department of Veterans Affairs, to research funded through a variety of program rubrics administered under the authority of a number of agencies and departments, to the role of CMS and FDA in reviewing and validating research into pharmaceuticals, medical equipment and other interventions, the interests and resources of the Federal Government play a major role in determining what gets evaluated, when and according to what criteria or standards.

Against this backdrop of these various incentives to outcomes and evaluative research provided with federal resources or under federal oversight, the question that arises is: What, if any, outcomes measurement is carried out in the health system of modalities of particular or specific relevance to health-system consumers with disabilities? The question applies in the area of treatment itself and in the realm of procedures designed to ensure effective outreach, follow-up, informed consent, compliance or the achievement of other system goals.

1D:6B. Other Research

The line between outcomes research and other types of research is sometimes difficult to find. But when it comes to research designed not to evaluate existing modalities but to create and implement new ones, government again plays major direct and indirect roles. Like evaluations research, these efforts can be regarded as incentives to the community, aimed at improving overall health.

Among these research efforts are a number that relate specifically to people with disabilities. These include earmarked research projects and funds administered by the National Science Foundation and NIDRR, including rehabilitation engineering research centers (RERCs) and

other rehabilitation research programs. While some of these projects are aimed at evaluating existing modalities within the medical or quasi-medical framework, including those designed to identify and promote best practices, others may be regarded as prospective in nature.

Such research may be regarded as an incentive to the community, usually taking the form of competed discretionary funding, available to a potentially broad range of contractors, grantees or program operators, for the designated purposes. Needless to say, the use of these research funds is tightly circumscribed by the terms of the award or competition under which they are forthcoming.

Any attempt to judge the overall impact of these and related research projects would require assessment of the mechanisms available for integrating findings into practice, and for drawing such connections between and among jurisdictionally or bureaucratically diverse programs and services as the data warrant.

1D:6C. Prevention and Public Health

Among the many types of medical and related research supported and encouraged by government, research into the prevention of disease represents an important category. As concern for long-term savings works itself into the policy equation at various points, the potential cost effectiveness of such research cannot be denied. For this NCD study the question is: How can such research be categorized in terms of the financial incentives with which are identified? Such research clearly is disability oriented but it typically offers little incentive of relevance to people with disabilities. Instead, the research is designed to create evidence-based data and sometimes behavioral incentives that will prevent the occurrence of conditions leading to disability.

Definitional ambiguities aside, such research remains controversial. Sectors of the disability community believe that prevention research, and “cure” research that bypasses efforts or resources designed to address the day-to-day realities of living life with a disability, actually result in the diversion of resources that might otherwise be available for incentives of one kind or another in the health care and lives of people with disabilities.

1D:6D. Long-Term Services and Supports

The line between health care and long-term services and supports or long-term care (LTC) is often difficult to draw. This line is important to everyone because of the overlap or gaps between public programs. But the distinction is particularly important to many people with disabilities who must face the vicissitudes of obtaining long-term services at a younger age than is typically the case for the general population.

As major research supported by NCD has shown, this country has no LTC policy. At the risk of making unduly fine distinctions among health care, income maintenance and long-term services, it is possible to identify programs that fall within the medical sphere, as discussed in the previous section, and as discussed in the next section, that provide income maintenance. Though no consensus, let alone legal definition, of the concept exists, LTC programs generally are distinguished by the nontraditionally medical nature of the services being provided, by the circumstances under which and purposes for which they are offered, by the non-cash nature of the services in most instances, and by other features.

1D:6D(i) Private Sector Insurance

The private sector has intricate connections that bind federal funding and tax policies to the kinds of coverage offered by that sector of the insurance industry. Private insurance coverage, all of which is tax-favored to varying degrees, involves the provision of specified institutional or home-based services to covered individuals who meet the requirements for benefits. Disability as such is rarely an absolute prerequisite to the receipt of benefits (though measures of severity of limitation apply). Ordinarily, activities of daily living (ADLs) are the baseline for determining entitlement to benefits under these policies. Home-based services up to a given dollar value or for up to a certain period of time may be authorized; for example, two ADLs (such as bathing, dressing, feeding, toileting, and so forth) cannot be performed independently. Institutional services such as nursing home residence, again subject to policy limits, will be authorized at varying but usually higher levels of severity, frailty or risk.

Nothing in the laws surrounding these policies overtly distinguishes between people with and without disabilities. It is widely assumed that inability to perform two ADLs would equate with

disability under any of a number of medical or ADA-type standards. This is not necessarily so, particularly if the major life activity at issue is the ability to continue living in one's own home. By the same token, people with sensory disabilities, communication disabilities, or mental illnesses, who need assistance with various functions in order to maintain a quality of life in their homes and communities, may not qualify for benefits, given the close association of ADLs with physical and cognitive abilities. Likewise in this connection, while it is certainly possible that individual insurers have provided AT to particular insured people under appropriate circumstances, research for this study has been unable to find any federal law that could be used, or at least that has been used successfully, to require provision of AT or home modifications under a private sector LTC policy. These AT and home modifications have, by contrast, been required under workers compensation insurance.

Insurers and insurance products (i.e., policies) are licensed by either state or federal regulators. One might suppose therefore that in the case of a community incentive such as LTC insurance, governmental regulatory and approval power would be used, if not to ensure the availability of goods and services of specific relevance to people with disabilities, then at least to guarantee nondiscriminatory treatment of people with disabilities in terms of coverage offered, premiums charged and related matters. Along similar lines, the tax benefits offered to both providers and purchasers of LTC insurance do not appear predicated on any demonstrated willingness by the carrier to provide coverage on terms of equality to people with disabilities, subject to legitimate underwriting and classification criteria stemming from age, objective likelihood of utilizing services and similar established variables.

Without any guarantees, the net result may be that adults with disabilities whose actual need for services may be little or no greater than those for people without identified disabilities, attributed perhaps to coping skills developed over a lifetime, may nonetheless be denied coverage or granted coverage only at higher cost. As such, governmental inaction or seeming even-handedness can constitute not an incentive for people with disabilities, but an anti- or disincentive to this group of citizens.

The broader question raised by this discussion is again one of definition. When plausible government action, undertaken within the scope of existing authority or recognized policy prerogatives, could result in more nearly equal opportunities for people with disabilities than may otherwise exist, does the failure of the government to implement such equality measures constitute or amount to a financial anti-incentive so far as people with disabilities are concerned?

1D:6D(ii) LTC Insurance-Medicaid Partnerships

One approach to LTC insurance coverage and through it to the provision of some long-term services and supports that does bear directly on people with disabilities is the LTC insurance-Medicaid partnership. Under this model private coverage and Medicaid coverage can be combined more seamlessly and with continuity in those states where it operates. Again, because of Medicaid's inclusion of disability as one of its eligibility criteria, such programs represent a financial incentive, to people with disabilities directly (if they receive funds at any point to recruit and pay their own caregivers) or to third parties (if the funds are paid directly to home care agencies, nursing homes, care managers or other support and service personnel).

1D:6D(iii) Medicaid

One measure of the difficulty encountered in determining where health care ends and long-term care begins can be seen in the ambiguous and overlapping role of Medicaid. Although Medicaid is a medical insurance program, it also may well be the second largest funder, behind only self-payers, of nursing home services in this country. It is in incorporation of this service as much as in anything else that the differences between Medicare and Medicaid coverage can be glimpsed.

In its coverage of long-term care, Medicaid makes few distinctions between beneficiaries with and without disabilities. Though these populations often face very different issues in when and whether they require institutional care, and in what their needs are in the context of such care, the Medicaid Program provides its incentives in an even-handed way that takes minimal account of these differences. Even the Civil Rights of Institutionalized Persons Act (CRIPA), while providing for a number of reviews and including other protections for the rights of people

in custodial settings, and while implicitly assuming significant lack of autonomy among such people, does not recognize the different risks that different institutionalized subpopulations may face.

As it relates to people with disabilities, the financial incentive involved in Medicaid coverage of nursing home care demonstrates this same relative inflexibility. For instance, states generally take the position that extra costs, such as for powered mobility or other AT devices, even if eligible for Medicaid coverage in the community, should be covered out of the facility's standard daily rate for residents. As with all of Medicaid, whether predominantly health or long-term-care oriented, it recognizes disability as an economic limitation but typically not as one requiring differentiation in services.

1D:6D(iv) Other LTC Supports

1D:6D(iv)(a) Senior Services

Senior services, provided through a number of sources, including community development block grants (CDBG), Older Americans Act, and a number of other federal funding streams, represent another financial incentive to community living. A preliminary review of such sources doesn't reveal any particular attention to disability, either in terms of its role in eligibility determination or in the identification and planning of services that eligible individuals may need. Programs to identify frail elders at risk of institutionalization may be presumed to focus on people who meet or come close to meeting accepted definitions of disability, but disability does not appear to be a formal criterion for the most part.

1D:6D(iv)(b) In-home Supportive Services

These largely state-based programs, sometimes including federal funds from Medicaid or other sources, while relatively limited in impact, represent a model that could prove of relevance as an incentive to continued community participation for people with disabilities. Because the number, funding levels, eligibility criteria and scope of services characterizing these programs change so much even from year to year, it is unwise to offer too many generalizations about them here. One thing that is clear is that, by law or by practice, such programs tend to focus on elders, thus ensuring that a fairly high percentage of people with disabilities will be included

among service recipients, but also largely excluding people with disabilities under the age of 65 from benefiting from the incentives represented by such programs.

A major cost issue with Medicaid, respite care, and other family support programs relates to their capacity to compensate family caregivers for their time and services. Any attempt by the nation to come to terms with the explosive costs for home- and community-based services will have to address this question. Its answers have implications for the relative value of current or future incentives to people with disabilities. Some glimpse of those implications may be found in an already existing program.

1D:6D(iv)(c) The Rehabilitation System

One may ask how the rehabilitation system, geared primarily to employment as it is, could have anything to do with home- and community-based long-term services. The answer lies in two established features of the Rehabilitation Act and two federal funding streams that exist under this Act.

1D:6D(iv)(c)(i) Homemaker Outcome

In VR the law specifies a number of outcomes by which a case can be closed. Traditionally, homemaker has been regarded as a successful outcome, meaning that when a case is closed with the service recipient trained to and able to function as a homemaker, the VR agency can claim credit for a successful case closure for a “status 26 outcome” in VR parlance.

Overuse of homemaker closures came under heavy criticism in the 1960s and 1980s. Resorting to this outcome goal was seen as an excuse for the inability to get people jobs or for the lack of effort in that arena. While the use of homemaker closures has declined dramatically, one underlying rationale for this outcome category remains valid and relevant—that equipping a person with a disability to function as a homemaker frees another family member to go out of the household in order to work.

A number of VR services, whether targeted under an individualized plan of employment (IPE) or targeted to this or to another sanctioned VR outcome, include components that are relevant

incentives to community living and participation, including various types of skills training, such as adaptive techniques, low-level assistive technology, or limited home modifications. As such, community living and participation is an incentive that is targeted directly to people with disabilities, and that provides support largely for the provision of goods and services by third parties. Moreover, the time-limited nature of these services, given the concept of case closure that informs VR, reminds us that services need not always be open-ended or long-term in nature to represent financial incentives to long-term community living. Presumably, the skills and resources provided remain viable for some time, and there is always the possibility, although reported to be fairly rare in practice but countenanced by the governing federal law, of reopening a case or applying for follow-along services if conditions or needs to which the system can respond undergo major change.

1D:6D(iv)(c)(ii) Independent Living Services

An important component of the Rehabilitation Act, aimed largely at people with disabilities who do not have paid employment as their immediate goal, and reflecting the evolution of attitudes toward self-determination over the past generation, is independent living funding. Provided mainly through the network of over 400 independent living centers (ILCs) that have grown up around the country, these centers have come to represent a vital community resource for people with disabilities. As such, the federal funds that contribute to their operation, whether through direct grants or contractual services, represent an important incentive to community participation.

Consistent with the independent living philosophy, rigid jurisdictional requirements for the receipt of these services are not imposed. Economic status and perceived ability to work are not issues. To be sure, the procedural rules surrounding the operation of ILCs receiving federal funds, together with the rules establishing their governance (such as rules for the composition of their boards), have grown more complex. But the range of services they provide remains consistent with the perceived needs of the population being served, subject again to emphases that may become more or less relevant with the passage of time.

As it relates to the characterization of services, allowing independent living services between direct, indirect, and community-based incentives is sometimes difficult. In its ideal expression, embodying as it does the availability of a broad range of options and interactions to anyone who wants or needs them, independent living services are best described as a community incentive targeted specifically to people with disabilities.

What are known as core independent living services are enumerated in the Rehabilitation Act. Subject to the possibility of change in the forthcoming reauthorization of the Workforce Investment Act (WIA) (the federal statute embodying the Rehabilitation Act), these include both mainstream services such as housing, and specialized services (with the peculiar exception of AT). Notwithstanding this omission, many ILCs are deeply involved in AT, either as service-providers under contract with state VR agencies, as demonstration or training sites working with state Assistive Technology Act funding, as partners in AT loan programs under the AT Act, or under other auspices.

1D:6D(v) Tax Aspects

We noted earlier that the tax system supports the purchase and sale of LTC insurance. It does this by allowing deductibility to the purchaser, both through the usual health expense mechanism and in some cases as a business deduction for self-employed people, and through the usual range of benefits that attach insurance companies who sell the coverage. But tax system subsidization of long-term services, care and supports in other respects does not live up to this encouraging standard.

When it comes to home-based services such as personal assistants (PAs) or housekeeping or similar services, the tax law maintains unwarranted and outmoded distinctions between deductible medical services and nondeductible personal ones. To enforce this distinction, tax compliance officials resolve doubtful cases by looking at the skills and qualifications of the service provider (e.g., nurse or nurse's aide) and the nature of services provided. Where both medical and non medical services are provided, some allocation between them may be required. By contrast, if one is in a nursing home for medical reasons, all one's costs related to being there are tax deductible.

Likewise, although the add-on costs of transportation attributable to vehicle modifications, for example, would be medically deductible, the entire cost of transportation is subsidized only when used for medical purposes. Although advocates believe that this limitation should be read expansively, present law still appears to support the notion that visits to ILCs for training or exposure to AT or peer counseling would not meet the applicable threshold for being classified as medical. Hence such costs would not be medically deductible.

Subject again to all the usual limitations on the medical expense deduction discussed above (including ability to itemize, 7.5 percent AGI threshold, sufficient income to absorb any available deduction in the year of expenditure, and one or two others), home modifications too are deductible. This deduction is of little practical value to most people who need such modifications.

The Earned Income Tax Credit (EITC) offers an incentive to home-care of people with significant disabilities in one interesting way. Whereas the credit, which is refundable and of great value to lower-income working families, normally can be used only by families with children, its upper age limit is waived for an adult child living and being cared for at home on account of disability. Since this age-limit exemption would not be available for adult children living in nursing homes, assisted living facilities, congregate care facilities or other community residences, this feature of the EITC represents one of the few tax law provisions or other legal provisions that differentially incentivize home-based or facility-based long-term services and living.

1E – Income Maintenance and Asset Development

INCOME MAINTENANCE

Depending on one's definition, income-maintenance and income-replacement probably represent the largest category of identifiable federal expenditures targeted to people with disabilities. Though varying in detail based on the prevailing assumptions at the time of enactment, all these programs take as their point of departure certain assumptions about the association of disability, in its own right or as mediated by inability to work, with poverty.

Looked at globally, income maintenance or replacement programs can be divided into two basic groups: those that provide cash and those that provide in-kind assistance. A classic example of programs that provide cash would be the programs administered by the Social Security Administration (SSA). A classic example of programs that provide in-kind assistance that is more or less the equivalent of cash is food stamps.

All of the nation's income-maintenance programs are open to people with disabilities. Indeed, through §504 of the Rehabilitation Act if supported with federal funds, or through the ADA if operated by state or local government, all such programs are required to operate in a nondiscriminatory manner. Let us examine those programs that, controlling for poverty, appear to have the greatest impact on the lives of people with disabilities, and that were designed with this population particularly in mind.

1E:1 – Social Security Disability Insurance

Social Security Disability Insurance (SSDI) is one of the two key underpinnings of the nation's social insurance system. Available to workers who have paid into Social Security and to their dependents, SSDI replaces income for those rendered unable to work by reason of disability prior to the usual retirement age. Benefit levels are predicated on meeting the SSA definition of disability, which includes both a diagnosis, a prognosis that the condition will last for at least a year or result in death, and a determination of the individual's inability to work. Although not means-tested, this linkage to the ability to gain income through work amounts as a practical matter to the equivalent of means-testing in many cases. Benefit levels are linked to the amount of time one has worked, and to one's wages or self-employment income during that time.

SSDI was first added to the Social Security Act as Aid to the Permanently and Totally Disabled in 1955. Its purpose, as a logical and humane corollary to a program of social assistance for retirees, was to provide a safety net of income replacement for those prevented from completing their working careers on account of disability, as well as providing a measure of protection for their spouses and children.

Although SSDI is vital to millions of American families, it is hard to characterize it as an incentive. Despite the suspicions of many about the program, it is unlikely that people would deliberately seek to become a person with a disability (as opposed to claiming falsely to have a disability) in order to qualify for SSDI. In the end, the program is a community resource, designed to ensure stability and prevent destitution and rapid downward mobility. It can best be described as a major clause in the social contract.

But while disability is a necessary precondition for SSDI eligibility, it is not a sufficient one. An individual can meet the SSA definition of disability beyond any possible doubt yet be ineligible for benefits because of the failure to have amassed the minimum 40 quarters of covered employment. Moreover, while the diagnostic and functional dimensions of disability may be fairly straightforward in many cases, the determination of whether someone can or cannot work is a much more subjective one. This is because it is a legal, not a medical or functional definition. Among other things, it looks to whether the individual could perform any work that exists in the economy, regardless of qualifications or experience, and regardless of proximity to the individual's home, and regardless of the services, supports and technology that might be needed in order for the individual to perform this hypothetical job. Fortunately, because no one is willing to find the individual this hypothetical job, or routinely pay the costs of making it accessible, or on the other hand witness large numbers of people with visible disabilities starving in the streets, the law has not been enforced literally. Yet, changes in official interpretations of its nominal provisions are unquestionably associated with increases or decreases in the number of people receiving benefits at various times.

Other variables created by the governing law have resulted in the removal of people from the rolls at times, not necessarily because they have experienced miraculous cures. Often it has been because of technicalities in reporting or in documenting receipt of income or capacity to earn income, a lack of cooperation, or for other procedural reasons.

Underlying these procedural vagaries, the fundamental problem that emerges is the SSDI treatment of disability, via employability, as an all-or-nothing, one-or-the-other matter. Yet

experience and commonsense tell us that in this society, with appropriate attention to training, technology, transportation and accommodations, most people can perform, and want to perform, productive work. SSDI increasingly has functioned to absorb the provision of a safety net for those people whose costs of employment employers and government were unwilling to bear, or whose potential for productivity was considered lower than the wage that society would demand they be paid.

A key factor in understanding the tool of SSDI as an incentive or disincentive in the lives of people with disabilities is its linkage to health insurance. Most people receiving SSDI also are eligible for Medicare. While some SSDI recipients will be able to maintain private sector insurance, assuming they had it when they worked, through the coverage of a spouse who works, or for a period of time through their former employment coverage under COBRA (subject to full assumption of the premiums and a 2 percent administrative fee) or through other affiliations, Medicare is as crucial or more so than cash benefits in the lives of many SSDI recipients. It is this close connection, resulting as it does in the potential loss of insurance coverage if work is obtained that does not include comparable insurance coverage, that perversely cements the relationship, and the destructive dichotomy, between disability and work in American public policy.

Put another way, and emphasizing the connection between income replacement and health care, Medicare through SSDI makes insurance available to certain non-employed people with disabilities, under circumstances where comparable coverage is not generally available to people without disabilities who do not work. Conceived of at a time when health insurance was not such a looming concern or as costly as it is now, and at a time when the numbers of people obtaining such insurance through their employment was growing, this linkage made good sense. The linkage was based on the further assumption that disability equated with medical need, and that a meaningful response to it therefore should include health insurance. Health insurance coverage represents perhaps the most important in-kind income-replacement strategy available.

1E:2 – Supplemental Security Income (SSI)

Supplemental Security Income (SSI) derives from many of the same premises as SSDI, but with several key differences. SSI extends the safety net to all people with disabilities regardless of age, and to all elders regardless of disability, who meet its strict income- and resource-eligibility standards. SSI also differs from SSDI in being strictly means-tested, beyond the capacity for earnings. Unearned income is taken into account in determining eligibility and benefit amounts, as are savings, along with employment. Lastly, SSI differs from SSDI in being linked not to Medicare but to Medicaid, meaning that the state plays two important roles in it that are not parallel to SSDI: the state may or may not add a state supplement to the standard SSI payment (the Federal Benefit Rate), and the state, through its discretion in administering the Medicaid Program, will determine to a large degree exactly which health services an individual will receive. For people whose route to eligibility comes through disability, rather than age, monitoring of disability status as well as of economic status becomes a standard component of the program.

Because SSI is a direct cash payment of a relatively unrestricted nature to people of any age, the question of how to define disability related to children has caused recurring debate. No tests of employability and no actual evidence of work performance are of much use in determining the eligibility for SSI benefits of children. In place of ability to work, Congress and the courts have wrestled with various functional definitions over the years.

On balance, at least as it relates to adults, the law governing SSDI and SSI eligibility alike has placed far more weight on diagnostic and medical assessments than on functional ones. To take an extreme case, what this amounts to is that if a person were unable to move, speak, or interact in any way, that individual still might not qualify for SSDI or SSI benefits in the absence of some plausible medical explanation for the condition. Short of such an extreme case, the problem that emerges is that while society has moved toward a contextually-based definition of disability such as that of the ADA, which looks to the nexus between a physical limitation and its impact on one or more major life activities, the incentives embodied in SSA programs continue to adhere to a strict medical model, at least regarding initial eligibility determination.

There is one other key respect in which SSI must be distinguished from SSDI. Where SSDI is an income replacement program, SSI is for income maintenance. While this distinction may seem slight, it is in fact very important. Among other things, it means that the benefit levels available to SSI recipients, even though they are by definition “poor,” which SSDI recipients need not necessarily be, are generally far lower than workers with disabilities can expect.

Not only is SSI a program that at best is aimed at maintaining people at or near poverty level, including formulas for “deeming” family or other household members’ income as shared by the recipient so that benefits can be adjusted, but it is a program that contains powerful disincentives to saving or to asset accumulation of any kind. While a web of provisions exists to mitigate the disincentive effects upon employment of the SSI rigid resource limitations, and allowing for the maintenance of health insurance coverage while work status is demonstrated and stabilized, as well as allowing for the saving of funds for self-sufficiency-related purposes, it is argued that the complexity, inconsistency and occasionally internally conflicting nature of these provisions combine to offset much of their positive intention. In this regard, it may be noted for example that such key work incentives as the Earned Income Tax Credit (EITC), while excluded from SSI income calculation, remain exempt from inclusion in countable resources for only nine months. Such money might of course be used during that nine-month window to meet the costs of Impairment-Related Work Expenses (IRWEs), or it might be deposited into an SSA approved plan for the achievement of self-support (PASS), but these options may be unavailable to many people. By far the more common and perhaps more sensible response will be simply to spend the refund, since if kept it could lead to countable resources exceeding the \$2,000 limit. Cost benefits and a possible demand for return of overpayments might all too readily ensue.

The work-incentive provisions in the law are intended as incentives to work and to saving for work-related or other self-sufficiency-related purposes. Whether these provisions have much effect in this regard cannot be known, but the low numbers of people leaving benefits rolls for work suggests that they do not. Whether work incentive provisions could have a significant effect if coordinated with other benefit, educational and employment programs, one can likewise only speculate, but the overwhelming likelihood is that they could.

1E:3 – Benefits Counseling

Benefits counseling, along with its associated training and technical assistance, is applicable to virtually all incentives in federal law and to all targeted populations for those incentives. Placement is here because direct financial incentives of cash payments made directly to individuals present perhaps the most vivid illustration of where and how such counseling can be useful.

Today almost every federal program of any size or note includes provisions for public education and outreach, and when enabling legislation or budgetary authorizations make no explicit provision for this component of their work, agencies find ways to use their Web sites or other means for public relations about all the good things they do. In terms of the incentives to program access and utilization represented by benefits counseling targeted to audiences in the disability community (including potential recipients and service-providers), two principal forms of such outreach efforts can be identified: information and training regarding the opportunities for people with disabilities embodied in mainstream programs, and information targeted specifically to people involved with disability-oriented programs.

1E:3A. Generalized Public Outreach

Generalized public outreach regarding mainstream programs takes many forms. From agency Web sites and hot-lines, to presentations at conferences, to public relations campaigns and a host of other means, government agencies and their partners, in delivering program resources or services, constantly barrage the public with information. In the fine print, so to speak, of these efforts often there is an equal opportunity notice, a disclaimer of any illegal discrimination, or an indication of a number or office to contact for further information or specialized assistance on accommodation, accessibility or other disability-related matters. These may be regarded as community incentives, perhaps only indirectly financial, but ones intended to have a specific impact on people with disabilities and to redound to their financial benefit.

A significant recent example of the attempt to ensure fuller participation of people with disabilities in a mainstream program is the joint effort undertaken by a consortium of nonprofit,

university and public sector agencies to make the services and resources of the Volunteer Income Tax Assistance Program (VITA) available to people with disabilities. Having the appropriate utilization of the EITC by these taxpayers as its immediate purpose, this effort has operated through the establishment of a variety of relationships between grassroots organizations, ranging from credit unions to ILCs, and VITA sites and sponsoring organizations.

The financial incentive represented by such efforts at inclusion is indirect. That is, it does not directly benefit people with disabilities, nor put appreciable money into the hands of third parties or into the community. What it does, much like job training, or education, in the longer-term might do, is create the conditions for the infusion of new financial resources into the community through enhanced utilization of the EITC by low-income working families that include members with disabilities.

1E:3B. Specific Public Outreach, Training, Technical Assistance and Train the Trainers Programs

Similar kinds of outreach occur in connection with programs that are specifically created for use by or to serve people with disabilities. Two models are of particular interest here: outreach that focuses on relevant public audiences, and specialized training and technical assistance given to intermediaries whose work involves direct and sustained contact with individuals with disabilities.

1E:3C. Civil Rights Enforcement

One need not tune into radio or TV for too long before encountering a public service announcement regarding people's rights to be free from discrimination and indicating sources of help if housing, job or other discrimination has occurred. Frequently these announcements list categories of discrimination that are not permitted. Almost always when such enumerations are provided, race, gender and nationality are listed. Disability sometimes is listed too, the uncertainty being a function partly of the coverage of the specific laws being relied upon and partly of other considerations.

Whether such announcements and related public education and outreach constitute financial incentives once again depends on a fairly expansive reading of the concept of incentive. Civil rights have an important economic dimension in the form of many benefits arising from equal treatment and opportunity. Beyond that, discrimination may on occasion give rise to damages or at least reimbursement for losses.

1E:3D. Narrowly Targeted Education and Outreach

Increasingly the Federal Government has viewed education and technical assistance as important components of civil rights enforcement, with respect to those components in their own right and as their use as alternatives to enforcement by litigation. As such, the Federal Government has sought to make available as much information as possible about such laws. Numerous technical assistance manuals, booklets, Web sites, Q & As, educational videos, speaker programs and other means have been used by the Department of Justice, the Equal Employment Opportunity Commission, the Access Board, the FCC, the Department of Transportation and the Department of Housing and Urban Development to inform employers, airlines, architects, and many other groups of their obligations under a variety of civil rights and accessible-design laws.

In particular, owing to the apparent persistence of widespread unfamiliarity in the building industry with applicable ADA and Fair Housing Act Amendments (FHAA) accessible-design requirements, and in view of the emphasis that HUD has placed on reports and statements on efforts to reach the building industry, fair housing enforcement appears an appropriate context for raising the question of how the value of these incentives can be measured or judged.

1E:4 – Protection and Advocacy Services

Perhaps the most vital example of highly specialized, targeted information-dissemination and counseling about benefits-related issues to people with disabilities is found in the programs implemented by state-based protection and advocacy programs throughout the nation. Under such rubrics as Protection and Advocacy for Developmental Disabilities, Assistive Technology, Voting Rights, Traumatic Brain Injury and several other categories, the organizations are

charged with certain responsibilities, including clarifying and communicating the meaning of these programs and helping (though now largely without the right to litigate against the government) to ensure that recipients understand and can maximize their rights.

In an increasingly complex program and regulatory environment, such dedicated, expert resources are becoming ever more crucial if individuals with disabilities and indeed communities are to benefit fully from many of the financial incentives theoretically available to them.

The Client Assistance Program (CAP) is perhaps the best-known variant of P&A services for a target population defined by disability, or by involvement with a disability-related service system. CAP programs, operating under the Rehabilitation Act, as amended, are designed to provide clarification and information (though again, not litigation) to individuals with disabilities in resolving disputes over services with their state VR agencies. They present yet another interesting window into the complexity of defining and analyzing financial incentives.

CAP programs are intended in large measure to ensure that VR service recipients are able to access the services they need. As such, they certainly qualify as gateway assets, meaning that access to these programs helps bring about access to financially equivalent tangible resources such as services, vouchers, AT, tuition, and other services authorized under the Rehabilitation Act.

But at the same time, reason exists for believing that CAPs save public funds by preventing some disputes from escalating to costly litigation. By helping to clarify misunderstandings in some cases, by informally brokering compromises in others, and by convincing service recipients that formal grievance processes, including administrative appeals or full-blown lawsuits would be fruitless, these programs in all likelihood do operate to prevent litigation in the VR area. As such, it is likely that they save the VR system money that otherwise might be expended in defending such suits.

ASSET DEVELOPMENT

In today's world, a great part of federal asset development policy involves efforts to strengthen, encourage and protect various sectors of society and the economy. As this section will show, a dynamic awareness of the changing nature and incredible complexity of these goals and the arrangements underlying them will bring us into contact with a number of areas of the law rarely discussed in relation to poverty or disability but increasingly central to the destinies of people characterized by these terms.

To begin discussion, the line between income maintenance and asset development often may be difficult to draw. For purposes of this paper, income maintenance and asset development should be distinguished from one another based on three criteria: the nominal purposes for which funds are provided; the conditions governing their accumulation, availability and use; and the frequency or regularity with which they are received.

Using this screening test, most programs and funding streams will fall predominantly on one side or the other of the line. Individual Development Accounts, for example, may be regarded as asset-development programs because their stated purpose is to provide capital for specified purposes, because penalties ordinarily apply to their withdrawal or premature use, and because, although funds are paid into them regularly, these funds are subtracted from plan-holders' income for most eligibility determination and other programmatic purposes.

By the same token, payments made under the SSI Program are a clear example of income maintenance. Amounts to be paid are based in part on ongoing expenses such as rent and are adjusted for household size; no expectation of accumulation exists or is ordinarily even permissible; and any accumulation above strict limits triggers penalties designed to offset the capital formation that has occurred. Of course, mechanisms such as PASS do allow for asset development through accumulation of capital to meet specified purposes, but these options are an exception, albeit an important and growing one, to the basic thrust of SSI.

Against this backdrop let us examine a number of key asset development strategies currently in use in this country, some disability-specific, others not, with a view to placing them in the context that has been established.

1E:4A. Bond Programs

Perhaps best known in the contexts of export guarantees to companies or disaster-recovery loans to individuals and organizations, the Federal Government plays a major role in economic activity through loan programs. Indeed, insofar as the federal deficit may in some sense be regarded as an intergenerational or at least inter-decade loan program, one may say that borrowed funds play a central role in almost every area of economic policy and activity.

The Federal Government also facilitates the use of loans by state governments for a variety of economic development and infrastructure purposes. It does this by the tax-favored treatment accorded to a variety of private and economic activity bonds underwritten by states, and by a host of tax-based and other measures designed to assist states in marketing bonds to finance a host of activities. With respect to all of these, the key question is the extent to which any of these programs are designed with people with disabilities in mind. A subsidiary question asks whether these programs, especially if designed to impact the lives and opportunities of people with disabilities in any specific way, actually do so.

It is a natural instinct, as well as a fervent hope, that broad-based economic development programs benefit all citizens. If a state or municipality provides tax breaks, bonding authority or other subsidies to a major manufacturer to locate a new plant within its borders, the jobs created will impact the economy in ways that benefit everyone. Leaving aside whether this is true, questions about the specificity and inclusiveness of planning are still warranted. Do such programs ever include commitments regarding the employment of people with disabilities among the new workers to be hired? Is accessibility ever made a formal requirement where retail facilities such as shopping malls are subsidized, or is that left to routine building code enforcement? Do any publicly-supported economic development programs target industries or activities that may be of particular relevance or applicability to people with disabilities?

Although instances abound in which the recipients of publicly-funded economic development incentives have pledged major discretionary contributions to education, health care or infrastructure in their host communities, during this study there was no indication that people with disabilities have been a specific object or topic of concern in these settings, except so far as medical research and care may be viewed by some as disability related.

1E:4B. Small Business Development

Through the Small Business Administration (SBA), the Small Business Innovation and Research (SBIR) Program, and a number of contractual preferences and set-asides, as well as through other methods, the Federal Government has sought to empower small business development among disadvantaged populations. These programs are best known, and have been most controversial, in application to businesses owned by people from diverse racial and ethnic backgrounds, but they also are well established in connection with women-owned firms. While SBA programs, such as the Section 8(a) Program, provide preferences to a number of populations, they expressly fail to do so for people with disabilities. Nevertheless, there are a number of other federal programs that attempt to provide economic development loans, grants, and technical assistance and other capital formation assistance specifically to people with disabilities.

1E:4B(i) The Randolph-Shepherd Program

Established during the Depression, the Randolph-Shepherd Program authorizes states to own vending facilities in public buildings and facilities. These facilities are then licensed to people who are blind to run as business operations, subject to certain controls and oversight by the state. Among the resources made available to the entrepreneurs participating in this program are capital for the purchase of equipment and supplies, and technical assistance aimed at enhancing business success. The financial assistance received by the Randolph-Shepherd Program participants is regarded as asset-development rather than income-maintenance in nature because the individuals' income is defined by the profit they derive from the business.

1E:4B(ii) Assistive Technology Loan Program and Telework

Two programs authorized under the Assistive Technology Act and administered by the Department of Education target loans for AT, vehicle modifications, telecommunications equipment or other technology directly to people with disabilities.

Operated by state partners who slightly differ between the two programs and from state to state, these programs utilize credit standards and provide repayment terms aimed at surmounting the otherwise often insurmountable barriers to credit market access facing many people with disabilities. Indications are that repayment rates have been very high, but the Administration, after initially being very supportive of such programs, does not appear to have looked on them, or on any portion of the Assistive Technology Act, with favor in its last two budget proposals. Nevertheless, Congress has continued to appropriate funds for the AT Act, which constitutes largely indirect financial incentives or gateway assets to many people with disabilities.

1E:4C. Individual Development Accounts

Individual Development Accounts (IDAs), as authorized under at least two major federal statutes, represent a creative new approach to breaking the proverbial cycle of poverty by assisting low-income people to obtain funds for saving toward specified purposes. Although the two laws differ, all of the permissible savings goals, toward which earnings can be put and to which matching funds may be added, can be regarded as involving asset development or acquisition.

To determine whether IDA programs have been designed to take the needs, situations or indeed the existence of people with disabilities into account, the following questions must be asked: Do their waivers of income- and means-based limitations include such limitations in programs such as SSI that are of particular relevance to people with disabilities? Are the programs marketed to disability-oriented community groups and are linkages encouraged or required between anti-poverty and disability-oriented community-based organizations? Are informational resources made available in accessible formats? Do the permissible asset-accumulation goals include AT, and/or accessible transportation vehicles, or do the goals reflect the extra costs of accessibility in a variety of situations?

As the number and character of IDA programs across the country grow, generalization on the points discussed above becomes increasingly hazardous. Yet, preliminary indications suggest that, by and large, the answer to most of these questions is no. Still it seems likely, given the considerable overlap between poverty and disability, that a significant number of people with disabilities may benefit, either directly as recipients or indirectly as family members, from IDA programs.

1E:4D. Industry-Based Subsidy Programs

Many major industries in this nation are the beneficiaries of federal subsidies, sometimes directly, often indirectly or through regulation. But whatever their form, these subsidies, including but not limited to tax subsidies, contribute significantly to the capital and resources of these industries.

Although not generally targeted to individuals (except as business owners in these industries), the question may fairly be posed whether industries that employ people with disabilities, that provide products or services of particular use to people with disabilities, or that seek to make their mainstream products and services more accessible to people with disabilities are recipients of these financial incentives.

1E:4D(i) Farm Subsidies

Although frequently the target of criticism as the number of family farms in America and the percentage of the population living on farms shrink, agricultural subsidy programs surprisingly have withstood these attacks and remain a major component of food, land use, rural development and related policies in this nation. To the degree that the AgrAbility Program was incorporated into U.S. Department of Agriculture (USDA) funding in the 1990s as a method for providing assistance to farmers with disabilities, some recognition of this population has taken place. The current status and the impact of this program have not been determined.

1E:4D(ii) Intellectual Property

Through copyrights, patents and trademarks, U.S. law, beginning with the Constitution, grants protection to intellectual property of a literary, scientific, or other original nature. Increasingly, in

recent years, intellectual property law has been seen and used as a tool in the effort by various industries to enhance their economic position and safeguard return on their investments. To the degree that the government has adopted and enforced laws that dramatically have broadened the scope of intellectual property and the length of time under which much of it is protected, grounds exist for asking how this financial incentive has affected people with disabilities.

1E:4D(iii) Print Media

In perhaps no area have the issues been as clearly drawn as in the area of the accessibility of print or electronic media to people with sensory or communications disabilities. From the legal right of people who are blind to scan copyrighted books onto computers in order to make them accessible, to the right of people who are deaf to have closed-captioning of the audio component of television programs and movies, these issues are being addressed within a rapidly evolving framework of laws ranging from the Copyright Act to the Telecommunications Act.

These laws are not without recognition of at least some of the access needs of people with disabilities, but much of the concern appears to relate to technologies that increasingly are anachronistic and falling into disuse. For example, the copyright law provides exceptions to the ban on unauthorized copying in order to permit materials to be reproduced in accessible formats by nonprofit entities for use by people with visual disabilities. Along the same lines, provisions strengthening the availability of accessible textbooks and instructional media in schools were added recently to IDEA. At the same time, there has been an increase in legal protections that give owners greater control of the modification of software, including software that determines how material can be displayed. Web-based educational materials largely have gone unaddressed by the law.

1E:4D(iv) The Internet

In the Telecommunications Act of 1996, Congress recognized the central role of telecommunications to full participation and included provisions in Section 255 requiring that the manufacturers of telecommunications equipment and the providers of telecommunications

services make these goods and services accessible to and usable by people with disabilities, to the extent readily achievable. The Telecommunications Act provides many financial incentives to such companies, and as such, requiring them to make their goods and services accessible was regarded widely as a matter of simple fairness. Perhaps the greatest financial incentive provided to e-commerce, which directly benefits all those who sell telecommunications equipment and services, is the law largely barring state taxation of Internet-based transactions. Yet, through a complex series of administrative interpretations by the FCC, no action by Congress to modify those interpretations, and court decisions, including most recently a Supreme Court decision bearing directly on the subject, at this point so-called information services are not covered by the accessibility provisions of Section 255. Without going too deeply into the details, it has emerged that the “communications equipment and services” covered by Section 255 constitute only traditional voice-based telephone usage, while all data, graphics, Voice over Internet Protocol (VoIP) and other cutting-edge electronic technologies are not regulated by the FCC and are not subject to accessibility laws. Ironically, it is these very cutting-edge technologies and services that, because deemed closely associated with economic and productivity growth, are the recipients of the greatest amount and range of financial incentives. The conditions for ensuring that those incentives will benefit people with disabilities have yet to be defined by regulation or legislation.

1E:4D(v) Government Procurement

Government contracts for the procurement of goods and services represent major financial incentives to industry. In light of the leverage value they command, such contracts have provided the basis for imposition of all manner of conditions and advancement of all manner of government policies. From requiring major defense contractors to admit and bargain with trade unions during World War II, to requiring federal contractors to participate in the drug-free workplace program a half century later, the carrot and stick represented by receipt or denial of federal contracts represents a powerful incentive. As important, despite some shrinkage of federal expenditure as a proportion of Gross Domestic Product (GDP), such contracts are likely to grow in importance in the coming years, particularly in light of the increasing use of private sector entities to deliver services, and in light of the increasing centralization of technology procurements.

Use of the federal contracting power to advance the cause of equality, through nondiscrimination and even affirmative action requirements, in the areas of race, ethnicity and gender, go back to the 1960s. Efforts to use this asset development financial incentive of contracts to ensure equality of treatment for people with disabilities, whether as employees or beneficiaries, likewise have been established in one form or another for more than 30 years. But implementation of such policy goals may be very different than in the cases of other disadvantaged or marginalized groups.

In the case of people with disabilities, equality of treatment often requires a degree of individualization, in the choice of accommodations or the structuring of tasks, that is diametrically opposed to the equality of treatment that often defines nondiscrimination for other groups. Moreover, accessibility of facilities, programs, goods and services is also necessary if the equality and nondiscrimination mandates are to be fully meaningful.

Through Section 508 of the Rehabilitation Act, Congress has taken its largest single step in addressing these added dimensions of equal opportunity for people with disabilities through government channeling assets to industry. The law does this by requiring that electronic and information technology (E&IT) purchased by the government be accessible to and usable by people with disabilities, including federal employees and members of the public where applicable.

Whether the transfer of federal funds as assets to industry for the performance of services or the furnishing of goods leads to full participation by people with disabilities in the benefits attributable to the industry assets or assets of nonprofit sector organizations depends in no small part on the interpretation and enforcement of the federal laws. Key questions raised in this context include: Do federal procurement processes treat Section 508 as an important condition, on a par with other federal policy goals embodied in procurement law? Are states required to adhere to similar standards in their purchase of comparable equipment when supported by federal funds?

These questions are far too broad to be answered here. However, a template can be suggested for addressing them. To the extent that employment, consumerism, public information or other benefits are expected among the end results of many contracts, it should be possible, through survey techniques and case studies, including laboratory experiments and usability tests where typical situations of access and use are replicated under controlled conditions, to determine whether people with disabilities can and do benefit or participate equally or continue to face barriers.

Each dimension of, and barrier to participation translates into financial costs and benefits, and into life probabilities or opportunities that have direct and, at least in the aggregate, measurable consequences. As with education, access of the kind promised and represented by these technology-related provisions and structures translates into employment, consumer participation, and community living. That these incentives are granted or withheld so indirectly, indeed so subtly, makes them no less important or real.

If current trends continue, it is likely that more and more national policy goals will be implemented through the private sector. As such, these less obvious, often lower-level decisions, though made with little focus on or attention to disability, may prove to have as great a financial impact on the lives of people with disabilities as will any of the more obvious and overt choices that are made.

1F – Housing

It would be difficult to overestimate the importance of housing in the lives and consciousness of Americans. In ways that are obvious to us and in ways that are not, housing options affect almost every other element of life. Housing affects multiple aspects of living—what public schools one's children attend, why commuter rush hours exist on the roads into and out of every city or town of any size in America, the zip-code-based offers received via mail, to the availability of broadband—and as such, housing is a principal determinant of how people live. As housing prices have risen, preoccupation with the subject among Americans also has grown. From speculation about rising home values to fears of displacement, from increasingly

lengthy commutes to rising homelessness, increasingly the subject has come to permeate consciousness.

For people with disabilities, yet additional layers, related to accessibility and affordability—insofar as accessibility bears upon the supply-and-demand equation—must be added to the discussion. Discrimination, too, inevitably plays a significant if unspecified role.

Concerns for people with disabilities include a look at direct federal appropriations such as rental assistance, the effect and usefulness of home ownership initiatives, construction and renovation, relevant tax systems, mortgage interest deductibility, low-income housing tax credit through state building code certification, and fair housing enforcement.

Our government has developed an elaborate web of funding streams and programs affecting public and private sectors and broadly aimed at increasing the amount, availability and quality of housing in this country. All of these affect people with disabilities and their families, with some directly targeted to this population and others impacting their lives as an incident of their broader sweep. This section will examine some major examples of each type, insofar as they involve financial incentives of the kinds explored and proposed by NCD.

1F:1 – Direct Federal Appropriations

Housing-related appropriations by the Federal Government take many forms.

1F:1A. Rental Assistance

To a limited extent, federal housing subsidies still include some rental subsidies that allow low-income people, and in some cases expressly allow low-income people with disabilities, to pay for rental housing that they could not otherwise afford. The role of such subsidy and voucher programs has steadily declined. Even when such programs were a more prominent component of national housing policy, and to the extent that they remain in use in conjunction with other programs, recognition of the issues facing people with disabilities appears to have focused on only one dimension of access. That is to say, while economic eligibility standards recognized the limited income and resources of many people with disabilities, for example, there never

has been any recognition in the Section 8 (or 811) Program that factors other than income, age or family size need to be taken into account in determining the amount of subsidy or the kind of housing that would be appropriate. Thus, these programs have not included sufficient elasticity to reflect possible needs for additional space, or the heightened costs imposed on affordability by the scarcity of accessible dwellings.

It seems likely that the value of direct financial incentives, or of indirect incentives in the form of third party payments to landlords, may have been undermined significantly or limited by this failure.

1F:1B. Ownership Programs

The programs that today chiefly characterize federal housing policy, as described in detail in several NCD reports over the past five years, emphasize home ownership as the primary goal of federal involvement, and as the principal measure of policy success. These programs take two basic forms: programs, many administered under §202, for the construction or renovation of housing that is then made available to appropriate buyers under variously subsidized conditions; and in some cases they also involve direct subsidies or rent-to-own demonstrations.

1F:1C. Construction and Renovation

Programs operating in this vein include requirements for the setting aside of specified percentages of developments for people with disabilities, including people with physical and sensory disabilities. Such provisions certainly operate as a financial incentive to the availability of housing for people with disabilities, but the emphasis again appears to be on the eligibility criteria more than on the design of the property. While accessibility requirements apply to all federally-assisted housing, it does not appear that any clear or up-to-date definitions exist of what constitutes accessibility for people with sensory disabilities. From visual-alert doorbells to “talking” microwaves, technologies do exist to make independent living more viable for people with sensory disabilities, but the incentives in no way appear to take these possibilities or their implications into account.

Similarly, with respect to the well-established and better-known criteria for physical accessibility, grounds exist for concern whether the value of the housing subsidies to people with disabilities are maximized. Such accessibility standards also must consider the larger challenges of needs-based program limitations on the ability of potential purchasers to aggregate down payments or meet even subsidized mortgage commitments and the integration of key infrastructure elements such as transportation, accessible commercial facilities, health care or other community-based resources. Faced with a perceived lack of coordination among housing, transportation, economic development and health care planners and programs, questions may be asked about whether the number of individuals with disabilities who can benefit from these subsidies is as large as it might be. Questions of just this sort have been raised by critics of the federal and state response to the Supreme Court's *Olmstead* decision.

1F:1C(i) Other Homeownership Initiatives

A number of other homeownership strategies, including subsidy, counseling and other programs, exist to facilitate and broaden homeownership. While the government frequently has cited increases in overall homeownership and in the percentages of group members from diverse backgrounds who now own their homes, no data tracking homeownership among people with disabilities have been published, but research indicates the percentages to be dramatically lower than for other demographic groups. From these facts alone—the relative failure of the government to articulate homeownership among people with disabilities as a goal of housing policy, and the comparative rarity of such ownership—it seems safe to ask whether the variety of homeownership incentive programs currently in operation are well suited to increasing this desirable outcome for people with disabilities.

One evolving strategy that may be of particular interest here is the IDA, described earlier in this chapter. Under the major governing law, one of the permissible savings and matching objectives is home ownership. But the dollar limits on how much can be aggregated, coupled with the time limits applicable to how long the account can be funded, appear to leave many participants far short of being able to afford a down payment. Preliminary research findings indicate that, whatever it may have done to advance other goals, the IDA has had limited

impact in increasing home ownership among its participants. Nor is there any reason for believing that if IDA participants with disabilities were studied as a subset, their results would be any better.

1F:2 – The Tax System

Few areas of life have a better known relationship to tax law than does housing. Not only is the deductibility of home mortgage interest familiar to most middle class homebuyers or homeowners, but it has played a major role in subsidizing the residential real estate market over the years. Even more complicated provisions of tax law play a comparably important role in connection with commercial real estate. Two provisions are particularly worthy of attention here.

1F:2A. Home Mortgage Interest Deductibility

The question to be asked about the home mortgage interest deduction is whether it represents an incentive to home ownership for people with disabilities. One's natural reaction might be to suppose that at least for some people with disabilities it does, but it may well be that for even more people with disabilities it has the opposite effect.

But how could this be? To the degree that capital accumulation for use as a down payment may be the chief obstacle to home ownership for many people with low income, and particularly for people with disabilities who are restricted by needs-based assistance programs from saving material sums, mortgage interest deductibility may increase their problem. Because mortgage interest is deductible, the price of houses is subsidized by the tax law. If mortgage interest were not deductible, the real carrying cost of a \$200,000 house would be higher than it is now. Because of this fact, fewer people could afford it at that price and its price would have to come down to a level that compensated for the lost tax deduction. As overall house prices rise or stay level, so too do down payments, as a percentage of those prices tend to remain high. Much of the tax deductibility of mortgage interest may help homebuyers to keep up with monthly mortgage costs; the same deductibility constitutes a potentially serious barrier to homeownership entry for many people with low income, including especially those with disabilities who have been hindered in their ability to save or invest.

In like measure, where the costs of accessibility drive up the costs of housing, the mortgage interest deduction takes this into account only in the crudest sense of allowing a larger interest deduction if one pays more interest.

The tax law does allow the costs of accessibility-related home modifications to be deducted, but only as medical expenses available to people who itemize. Interest on home-improvement loans in certain circumstances and up to certain limits may be deductible, including when structured as home equity borrowing, but the parameters are complex and there is no special dispensation (except again potentially under the medical expense rubric) to ease or simplify the deductibility of interest attributable to such loans when their purpose is accessibility.

Even when it comes to the medical deductibility of home-modification expenses, the interpretation of the law and rule relies upon a definition of accessibility that prevents this financial incentive from being of use to nearly as many people as it could or should. For the deduction to come into play, changes need to be made to the home itself. Other disability-related factors, such as proximity to public transit for people prevented by disability from driving, proximity to medical facilities for people with health conditions, or proximity to key community-based resources crucial to the avoidance of institutionalization, may all play a role as important as the actual physical condition of the home in determining whether an individual with a disability can live in it. These factors, by restricting choice, may drive up cost, and they are every bit as much matters of accessibility, but, apart from the tax deductibility of the larger mortgage interest payment, the tax law accords them no recognition. As such, the law chooses to treat as mere matters of preference or convenience issues that are of central importance to the availability and usability of housing and to the ability of many people to live in the community. It is not far-fetched to suggest that the presence of a traffic light, a curb cut, a bus stop or some other public amenity or private facility may go a long way in determining the accessibility of a given home for a person with a disability.

A related problem should be noted in connection with the interplay between tax and civil rights laws relating to rental property. The ADA and the Fair Housing Act Amendments make clear

that a rental tenant who needs to make accessibility modifications generally has the right to do so, provided he or she is willing and able to pay and provided the property is restored to its original condition when the tenant moves out. Although not as clearly articulated in the law as some might like, there appears little doubt that the costs of the modifications also qualify for medical-expense deductibility. Regrettably, people contemplating the use of the tax system to subsidize such costs must reckon with the fact that the costs of restoration of the property to its original condition likely will not be subsidized. Curiously, the owner's costs, if incurred either to implement the modification or to remove it, would qualify for deductibility routinely in the context of the owner's business activities of producing rental income and owning rental property.

1F:2B. Low-income Housing Tax Credit

The Low-income Housing Tax Credit (LIHTC) allocates specified sums to the states for use in subsidizing various housing projects for people with low income. The logic is that if developers receive tax benefits for building such housing, they will do so, thereby bringing down, both directly and indirectly, the costs to the occupants.

While it is clear that people with disabilities are represented among people with low income whose access to housing has been enhanced by this financial incentive to a third party, nothing in the law itself rewards developers for designing or building in ways that would make these facilities more accessible than what the law minimally requires. Many approaches could be fashioned that, consistent with well-understood precepts of tax administration, would encourage accessibility and heightened outreach to people with disabilities. In a growing number of states, the competitive process for awarding the LIHTC has begun to provide a competitive advantage to developers who consider affordability and accessibility needs of people with disabilities.

1F:2B(i) State Building Code Certification

Building codes are an important incentive to many health and safety goals because the codes obligate private sector entities to expend funds and implement designs that meet certain standards. ADA compliance is among these.

Under the ADA, the Department of Justice (DOJ) can certify state building codes as meeting the requirements of the ADA. Once this is done, although such certification does not totally immunize states against suits, considerable certainty is thought to be brought to the building community and to the permitting process. But as an inducement to ensuring developer investment in accessibility, DOJ certification may or may not be effective. Much depends on whether the states, after certification of their building codes, systematically enforce them. Regrettably, nothing in the ADA appears to contemplate regular monitoring or oversight of such enforcement, and unless there is a complaint regarding failure, laxity may never come to light.

1F:2B(ii) Fair Housing Enforcement

To the degree that fair housing laws are vigorously enforced, including through the levying of maximum fines for violations, fair housing laws can represent a financial incentive to people with disabilities. Faced with a risk of incurring costs for violating the law, building designers, owners, rental agents, etc. are less likely to engage in discriminatory practices, provided the risk of apprehension is real. This would in turn expand the supply of available housing, hence bringing down costs.

After a period when enforcement seemed to focus largely on education and technical assistance, some renewed balance appears to have been introduced into the system by the Department of Justice (DOJ) levying fines against major builders and apartment complexes over the past two years. What would be crucial to making such penalties become financial incentives instead, would be the degree to which others regard the risk of similar consequences as serious, and the extent to which the practices of the respondents in these cases have been permanently altered. The point here is that deterrence can, in certain circumstances, have significant economic implications not merely for the entities or individuals being deterred but also for those affected by their conduct. Subject to the difficulty of designing reliable methodologies, an attempt should be made to conduct research that would probe the leverage value of such deterrence

and that would assess its impact on the supply and thus the cost of housing for people with disabilities.

Item 2 – APPENDIX B: BACKGROUND OF 529 PLANS

There are a number of ways to save money for a child's education. Two of the more popular are the *Coverdell Education Savings Account* (ESA) and state-sponsored college-savings plans commonly referred to as 529 plans. Among the advantages are tax benefits and asset control. Although contributions to either an ESA or a 529 plan are non-tax-deductible for federal income tax purposes, earnings on the contributions grow tax deferred. In addition, accumulated funds may be withdrawn free of federal income tax if used for qualified education expenses.² The question is: can these asset-building techniques become widely inclusive of individuals with disabilities, offering them better educational opportunities?

The 529 plans are recent developments, but the plans are gaining in popularity because of their tax advantages and contribution limits. You may contribute up to the limit set by the state offering the plan, sometimes over \$200,000, and there is no income limit for contributors. The Federal Government allows yearly contributions from single taxpayers of up to \$12,000 or a lump sum of \$60,000 in the first year of a 5-year period to avoid gift-tax consequences. Married couples may contribute up to \$24,000 per year or \$120,000 in a lump sum for that first year contribution.³

ESA and 529 plans also offer the ability to transfer the assets to another child if the intended beneficiary does not attend college or does not use all of the assets. The beneficiary must use or distribute the assets of an ESA prior to becoming 30 years old. Thirty days after the beneficiary turns 30, the assets are deemed distributed and are subject to all taxes and penalties. There is no age limit on the use of 529 plan assets.⁴

The 529 savings plans have public (state government) control and a centralized accounting system, which together constitute a policy structure that has the potential to be universal and progressive, and give everyone an account at birth and give greater subsidies to low-income households.⁵

With 529s, in contrast to IRAs, inclusive innovations are occurring at the state level. Typically administered by the Treasury Department through a centralized plan, states dictate rules and oversee plan participation. Some states have a commitment to inclusion (with 529 plans) that does not occur with IRAs. These include much lower minimum deposit requirements, extensive outreach, matched savings and other features.⁶

The direct involvement of state governments in 529 plans is beneficial for examining how a centralized system of inclusive accounts could operate in the future. Ultimately, a national savings plan may be preferable to 50 different state plans, but as in other areas of policy development in the United States, experimentation in the states can help set the stage for a national plan. Different approaches in the states can help identify the best policy features.⁷

Many states are trying to reach a broad population. Outreach activities vary by state. The most often-used methods to communicate are television, radio, and print advertisements. Efforts to reach wide segments of state residents include inserting 529 plan information with mailings for birth certificate and motor vehicle registration, and distributing information via school systems, libraries, and day care centers.⁸

A majority of plans require very low minimum contributions. In many states, people may open accounts with a \$25 check, money order, electronic funds transfer, or with as little as \$10 through an automatic plan deposit. Extensive efforts also are made for workplace enrollment.⁹

Three states, Michigan, Minnesota and Louisiana, provide a savings match through state appropriations. The Louisiana Student Tuition Assistance & Revenue Trust (START) 529 savings plan matches a portion of deposits made by all state residents, with the match rate dependent on the adjusted gross income (AGI) of the account owner. The savings match rate ranges from a high of 14 percent of contributions for

those families with an AGI up to \$29,999 to a low of 2 percent for incomes of \$100,000 and above.¹⁰

College savings plans may provide good partnerships with Individual Development Accounts (IDAs). Several states encourage participation in college savings plans by low-to-moderate income families through matched savings. Other states already have links to IDAs. These precedents for outreach and inclusion may offer lessons for future policy and program development.¹¹

Item 3 – Appendix C: Research on Promising State Innovations (Identified According to Domains Affected)

3A – Education: Louisiana START Program

Louisiana’s Student Tuition Assistance and Revenue Trust (START) Savings Program

START is a program that encourages families to save for the education of their children and grandchildren after high school. Parents, grandparents and legal guardians may establish a college savings account to benefit their child or grandchild. The feature that makes the START Savings Program unique among savings plans is that for the average family that has less than \$100,000 in annual income, the state of Louisiana will award an incentive to save by matching a percentage of the family’s annual deposits. Deposits into individual accounts are pooled, invested and managed by the State Treasurer.¹²

The program charges no enrollment or investment fees because the state pays all the costs of operating the program, which is assurance to account holders that every cent deposited will earn interest to their benefit. Parents may open a college savings account for each of their children and are encouraged to make regular monthly deposits into these accounts. Deposits and state-awarded incentives both earn interest at competitive rates, and earnings used to pay the cost of education are not taxed by the state. Federal taxes on earnings are deferred until the earnings are disbursed and then taxed at the beneficiary’s tax rate when used for educational expenses.¹³

As of the end of the state fiscal year, June 30, 2003, START accounts totaled 9,170 and assets amounted to \$27,802,406.83, according to START Division Director Carol Fulco. At that point in time, Fulco said net contributions to accounts totaled \$26,887,374.18. Effective August 1, 2003, the new Maximum Allowable Account Balance (MAAB) will be \$197,600.¹⁴

START earnings exceeded projections during the first two quarters the program was in existence. Louisiana State Treasurer of record, Ken Duncan, reported earnings for the fourth quarter of 1997 in excess of 6 percent for both investors' deposits and the state's grant funds. START funds, which are placed in the State Treasury investment pool and in Agency securities, outperformed treasury bills, certificates of deposit and passbook savings accounts for both third and fourth quarters.¹⁵

Duncan said that investor funds (START account holder deposits) earned an annualized rate of 6.12 percent for the fourth quarter, while grant funds (state appropriations earmarked for matching Tuition Assistance Grants) earned an annualized rate of 6.46 percent. The combined annualized earning of investor and grant funds was 6.12 percent. The average daily account balances as of Dec. 31, 1997, were \$442,074 in the investor fund and \$108,729 in the grant fund.¹⁶

Louisiana Office of Student Financial Assistance Executive Director, Jack Guinn, praised the many public libraries across the state for playing a vital role in making the program a success during its inaugural enrollment period. The state's libraries served as distribution points for START program enrollment materials.¹⁷

In the latest *529 Plan Report*, Louisiana's START Program earned the highest rate of return of states reporting earnings for the first half of 2002, according to Louisiana State Treasurer John Kennedy. START's annualized rate of 6.12 percent exceeded all other state plans regardless of whether their savings options were age-based, fixed income investments or equities.¹⁸

START is categorized as a 529 plan with the lowest market risk because its monies are diversified in a variety of fixed income investments like government bonds and notes.

The Treasury plans to diversify START even further next year by expanding account holders' investment opportunities to include equities.¹⁹

In addition to earning interest on diversified investments, START accounts receive matching funds from the state. The state matches 2 percent to 14 percent of START deposits depending on income and Louisiana residency. Historically, START accounts have earned 8 to 20 percent on annual deposits.²⁰

The Louisiana Legislature, with the passage of State Senate Bill 690 authored by Sen. Fred Hoyt (D), enhanced the benefits of START and enabled any benefactor to open an account for the purpose of assisting a student, the intended beneficiary, in paying for their college education. Originally, a START account could only be opened by a parent, grandparent, legal guardian, a person claiming the beneficiary on their federal income tax return, or an independent student who named him/herself as the beneficiary. The new law will permit accounts to be opened by anyone who wishes to assist a designated beneficiary in paying for his/her college education, including relatives, employers and other benefactors. Eligible account owners are categorized as follows:²¹

1. *Category I* - Original Class: Parents, grandparents, court-ordered custodians, [people] claiming the beneficiary as a dependent on their federal income tax return, and independent students, if, at the time of the agreement, either the account owner or beneficiary is a resident of the state.
2. *Category II* - Members of Family: A person [or people] determined by the administering agency to be a member of the family of the beneficiary and, at the time of the agreement, the beneficiary is a resident of the state. Members of the family include adults related to the beneficiary as brothers, sisters, aunts, uncles, spouses, in-laws, step-parents and step-siblings.
3. *Category III* - Other Persons: Any other person or juridical entity and, at the time of the agreement, the beneficiary is a resident of the state.
4. *Category IV* - Other Persons/Non-Resident Beneficiary: Any other person or juridical entity who, at the time of the agreement, is a resident of the state and the beneficiary is not a resident of the state.

In addition to regular earnings on investments, owners whose accounts are in Categories I and II will receive a contribution from the state to match a percentage of their annual deposits, ranging from 14 percent to 2 percent and determined by the account owner's prior year income. Owners of Category III accounts will receive state contributions that match 2 percent of annual deposits. For example, if an employer opens a Category III account for the benefit of an employee's child, that account will receive an annual state contribution that will match 2 percent of deposits made by the employer during the year. Owners of Category IV accounts are not entitled to state matching contributions; however, earnings on their investments will be tax-exempt and the owner may deduct up to \$2,400 per year, per account, from their Louisiana taxable income.²²

Previously, START account owners were offered tax advantages in several forms, one of which was the ability to deduct the equivalent of their annual deposits in a START account from that year's state taxable income, up to a maximum of \$2,400 per account. The new law will benefit families who cannot take full advantage of this tax benefit every year, by allowing the owner who claims less than the maximum \$2,400 per year to carry the difference forward to subsequent years. The state's contributions to an account will no longer be restricted to the payment of tuition expenses and can be used to pay any qualified higher education expenses. Other program enhancements contained in the legislation include: accounts receiving annual deposits of less than \$100 are now eligible for earnings enhancements; and, the calculation for earnings enhancements will be based on the account owner's adjusted gross income reported for the previous year, which permits earnings enhancements to be allocated to accounts sooner and to earn additional interest. In addition, state Senate Bill 690 authorizes the Louisiana Tuition Trust Authority (LATTa), the administering agency for START, to create other investment options that will be made available to all classifications of accounts. One option will limit investments to low-risk securities that provide a stable, fixed return, while other options will permit investments in stocks and other securities that have market risk, but which offer the potential for greater returns over time. The redemption value of accounts invested in low-risk securities will be guaranteed. However, those

investment options that include market risk will not be eligible for state-funded earnings enhancements, nor would investments (principal and earnings) be guaranteed.²³

During the same week that the Louisiana Legislature completed action on Senate Bill 690, the U.S. Congress agreed upon revisions to the federal tax code that govern qualified tuition programs, such as Louisiana's START Savings Program. As part of a \$1.35 trillion package of tax cuts spanning the next 10 years, the U.S. Congress passed HR 1836, the Economic Growth and Tax Relief Reconciliation Act of 2001, which eliminates taxes on the earnings portion of disbursements made from Louisiana's START Savings Program. Previously, earnings from contributions made to qualified tuition programs were exempt from state tax, and federal tax was deferred until earnings were disbursed. Upon disbursement, the earned interest portion of the disbursement was federally taxed at the beneficiary's usually lower rate. The new federal legislation excludes the earnings portion of a disbursement from gross taxable income, to the extent that the disbursement is used to pay for qualified higher education expenses.²⁴

The final version of HR 1836 includes the following additional enhancements to Louisiana's START Savings Program and to other qualified state-sponsored tuition programs:

1. Expands the amount of room and board expenses that may be paid from a qualified tuition program.
2. Provides for transfers of credits, or "rollovers," from one qualified tuition program to another qualified tuition program for the benefit of the beneficiary, limiting such rollovers to one per 12-month period.
3. Revises the definition of "member of family" to include first cousins.
4. Modifies the definition of qualified higher education expenses to include expenses of a special needs beneficiary that are necessary in connection with his or her enrollment or attendance at the eligible education institution.

All provisions in the federal bill relating to qualified tuition programs were either suggested or endorsed by the National Association of State Treasurers (NAST) and the

College Savings Plan Network (CSPN), of which Louisiana is a member. The majority of the provisions were effective for taxable years after Dec. 31, 2001.²⁵

The Louisiana Tuition Trust Authority has approved two emergency rule changes. One eliminates restricted enrollment periods, thus allowing year-round enrollment. The prior rule established a restricted enrollment period of July 1 through November 1 of each year for children over age one. Infants younger than one year of age were allowed year-round enrollment.²⁶

The Louisiana Legislature also approved legislation incorporating recent amendments to the Internal Revenue Code (IRC) that affect the state's START Program. Section 529, Internal Revenue Code, was amended by Congress, to allow the inclusion of room and board costs as Qualified Higher Education Expenses. Other principal features of the amendment are clarification of the gift tax treatment of contributions and an expansion of the definition of family members for purposes of rollovers and distributions. A bill introduced by State Representative Charles McDonald (D), which would amend current state law so that it would be consistent with changes to the IRC, became law in July of 1999. This legislation broadens certain savings limitations, making the START Program more beneficial for participants.²⁷

In 2003, Louisiana Governor M. J. "Mike" Foster signed into law SB 271, Act 221, making further changes to the START Program. Act 221 provides four new provisions for the administration of and participation in the START Program. The Act adds a new category of account owner to provide a higher state match for irrevocable donations made by philanthropists on behalf of needy students, provides that an account must be open for 12 months in order to earn interest, determines that accounts established by juridical people may not be refunded, but a beneficiary may be designated, and provides for the presumption of abandoned property if abandoned for a certain period of time.²⁸

3B – Long Term Services and Supports - Missouri Assistive Technology Program

Assistive Technology Legislative Initiative

Missouri has many programs that effectively target individuals with disabilities by providing them with support for assistive technology to increase their independence and quality of life. Introduced and sponsored by Missouri State Senator Harold Caskey, SB721 was designed to improve statewide programs for individuals with disabilities in Missouri, and became law in August 2000.²⁹ This Act revises programs for people with disabilities to enhance access to telecommunications, and to enable access to other assistive technologies.

The Missouri Assistive Technology Advisory Council, as the program administrator, will provide a statewide telecommunications equipment and distribution program for people who, due to a disability, cannot use traditional equipment.

The Public Service Commission will request annually, as a separate budget item, appropriations from the deaf relay service and equipment distribution program fund to deliver dual-party relay service. The Missouri Assistive Technology Advisory Council will request annually, through a separate line item, an appropriation from the same fund to deliver the telecommunications equipment distribution program.

The Act also requires the Missouri Assistive Technology Council (Assistive Technology Council) to establish an Assistive Technology Loan Program.

The Assistive Technology Council shall spend available moneys in four equal shares each quarter to ensure that the loan program will provide loans throughout the entire fiscal year. The Act creates the “Assistive Technology Loan Revolving Fund,” which shall be used to fund the Assistive Technology Loan Program.

The interest rates for loans shall be lower than comparable commercial lending rates and shall be established by the Assistive Technology Council based on the borrower’s ability to pay. Loans may be made with no interest. Loan repayment periods shall not exceed ten years. The Assistive Technology Council shall promulgate rules to

implement the program and file annual reports with the Governor and General Assembly.

Impact of Federal Legislation

On October 25, 2004, President George W. Bush signed into law the Assistive Technology (AT) Act of 2004 (HR 4278). The legislation supporting state assistive technology programs was scheduled to sunset on September 30, 2004. The AT Act of 2004 supports the continuance of state AT programs and eliminates the sunset provision. Every state and U.S. territory has an Assistive Technology Act Program funded under the provisions of the Technology-Related Assistance Act of 1988. The AT Act of 2004 focuses on the development or continuation of specific programs that ensure direct access to technology, including assistive technology loan programs, device demonstration programs, device reutilization programs, and alternative financing.³⁰

In addition, AT programs are responsible for implementing training and technical assistance, with special emphasis on assistance for individuals with disabilities who are transitioning from school to work or continued education. The AT programs also are responsible for conducting public awareness activities, information and referral services, and coordination and collaboration with public and private entities that are responsible for programs, services, policies or funding of assistive technology services.³¹

The AT Act of 2004 also clarifies states' responsibilities to ensure access to electronic and information technology as defined under Section 508 of the Rehabilitation Act of 1973. Activities carried out under and supported with federal funds received under the AT Act of 2004 are required to comply with Section 508 standards.³²

The ADA and Section 504 of the Rehabilitation Act do not specifically require information technology accessibility as does Section 508. The ADA and Section 504 are general anti-discrimination laws that require program and architectural accessibility, which could include the provision of accessible information technology as a reasonable accommodation or as an auxiliary aid or service necessary for equal access. The

effective communication requirement of the ADA could also require the delivery of accessible information technology products. All of these requirements also might be met in other ways, such as by the use of human assistance or other program modifications. ADA and Section 504 information technology access decisions are made for individuals on a case-by-case basis, whereas Section 508 information technology access decisions are made by determining if products adhere to the Access Board standards. At the writing of this report, the Department of Justice has not adopted any part of the Access Board standards for IT access as standards for compliance with the ADA or Section 504.³³

For purposes of Section 508, Missouri defines its covered entities as, “Each department, office, board, bureau, commission, or other unit of the executive, legislative, or judicial branch of state government, including public four-year and two-year colleges and universities.”³⁴

Missouri defines information technology as, “Any electronic information equipment or interconnected system that is used in the acquisition, storage, manipulation, management, movement, control, display, switching, interchange, transmission, or reception of data or information, including audio, graphic and text.”³⁵

Missouri requires covered entities to provide access when developing, procuring, maintaining or using information technology so that individuals with disabilities have access to and use of information and data that is comparable to what is available to individuals without disabilities.³⁶

Overview of Missouri’s Assistive Technology Program

Established by state statute in 1993, the Missouri Assistive Technology Council (MoAT) directs programs and initiatives pertaining to MoAT. The Council’s charge is to serve as an advocate for policies, regulations and programs and to establish a consumer-responsive, comprehensive assistive technology service delivery system. The Council meets at least four times a year, reports annually to the Governor and the general

assembly on Council activities to increase access to assistive technology, and provides programmatic direction for all activities and services.³⁷

For the third year, the Division of Special Education provided funding to MoAT to reimburse school districts for assistive technology required in student IEPs. Districts applied for funding to MoAT for assistive technology expenditures. The minimum cost per student supported was \$1,000 and the maximum was \$5,000. It is hoped that additional funding will be available next school year.³⁸

Also in 2005, the MoAT Program Equipment Technology Consortium (ETC), which is a short-term equipment loan program, received funding through the Blindness Task Force in the Division of Special Education to increase the availability of vision-related adaptive devices in the loan pool. This reduced wait time for equipment in ETC. A little over \$30,000 in additional funding was made available.³⁹

MoAT staff provided training on assistive technology to 1,824 Missourians through 30 other training events. People on MoAT staff assist individuals with disabilities and service providers on a daily basis through phone and e-mail. Assistance is provided in obtaining assistive technology, securing device funding, accessing the various MoAT programs discussed in this report, and gaining disability policy knowledge. During this fiscal year, MoAT staff handled 17,957 inquiries and requests for assistance by telephone and e-mail. The major topics of discussion are listed below.⁴⁰

For the past 10 years, the state of Missouri has imposed a 13-cent surcharge each month on every telephone line in the state. Whether business or residential, mobile phone, or land line, the surcharge is collected and moved directly into a fund for making telephone equipment accessible to Missourians unable to hold a conventional telephone or hear or speak on one.⁴¹

“The money was growing,” explains Dennis Miller, a disability rights advocate and assistive technology trainer, “but there wasn’t much awareness of it, and it was seen as helping only deaf people.” Last year, such organizations as the Missouri Council of the

Blind, the National Federation of the Blind, and others worked in collaboration with the Missouri Assistive Technology Project to expand the purpose of the fund.⁴²

Telephones

The Missouri Assistive Technology Project has identified phones in every imaginable configuration to solve the telephone access problem for people with hearing and other disabilities. TTYs (also known as TDDs)—telephone devices that connect to a phone line and allow the user to type messages that are read on a similar device at the other end of the conversation—are the most commonly known adaptive telephone devices. Add to this telephones with large buttons for easy visual identification; phones with Braille buttons; phones that respond to voice commands for dialing; phones that have no handset, but are speaker only; phones that allow a deaf person with use of his or her own voice to speak output but read input on a two-line display; phones that amplify the voice of an individual with speech difficulties or minimal vocal strength; amplification at every level—some that can even damage the hearing of a listener without a disability; phones that can be dialed by puffing through a straw; and many more. Some telephones on the approved list can be obtained through prescription only, but all can be installed with accompanying training from the Missouri Assistive Technology Project. Diane Golden, director for the Missouri Assistive Technology Project, explains, “Now, we have about 10 people around the state who help consumers figure out what will meet their needs. If consumers didn’t know what to choose, they chose nothing. The service almost immediately doubled when it was moved over to our office last August. The reason is that we added this consumer support piece to help people make sense of the vast array of choices.”⁴³

Online Access

When the wording was drafted to expand the scope of the program, the initial idea was to assist blind and visually impaired Missouri residents in obtaining screen readers. The actual outcome goes well beyond those intentions. Although there is a list of recommended products, virtually any hardware or software that will make it possible for

a person with a hearing, vision, speech, mobility, or other disability to access the Internet can be purchased under the Adaptive Telecommunications Equipment Program. For blind people, in other words, this could mean Window-Eyes, ZoomText, or JAWS for Windows—programs that enable the consumer to read the screen—but would not include a Braille printer or optical character recognition system, since these products are not directly related to Internet access. Screen readers, magnification software, refreshable Braille displays, head pointers, voice recognition software, and alternative keyboards are all products on the approved list of purchases. Perhaps the best news is that if you are eligible for the program, you also receive training to get you up and running.⁴⁴

Eligibility

To be eligible for the Adaptive Telephone Equipment Program, a Missouri resident needs to have a standard telephone line and a disability that prevents conventional telephone access. Eligibility for the Adaptive Telecommunications Program requires that an individual first have access to the Internet (an Internet service provider) and a disability that prevents online access through a conventional computer keyboard or monitor. “If you didn’t have a disability, you’d need a basic computer,” Golden points out. “What we’re doing is just adding to that basic equipment whatever is required for access because of the disability.” The program will fund the additional accessories required for going online, but not the computer itself. The Missouri Assistive Technology Project also administers a low-interest loan program, which can be used as a means to securing the basic computer.⁴⁵

As long as the applicant earns less than \$60,000 annually and has a certifiable disability, no other criteria need to be met. Trainers are evaluated and certified by the Missouri Assistive Technology Project to work with program participants once equipment has been selected and purchased. A waiting list of about 150 applicants already has been approved (the majority of them blind or visually impaired), and as soon as purchasing contracts have been released, the first year of the Adaptive Telecommunications Program will be off and running. Although many states have

programs to help people purchase telephone equipment, Missouri is the first to expand such a program to include the purchase of screen readers and other equipment for Internet access. In keeping with the “show-me” tradition, other states could learn much from this Missouri model.⁴⁶

Missouri Rehabilitation Center

Missouri Rehabilitation Center is home to one of the best-equipped assistive technology centers in the state. The Assistive Technology Assessment Center has been serving the needs of pediatric and adult inpatients and outpatients throughout the state of Missouri since 1997. Among the people receiving service are individuals who present sensory, motor or physical disabilities that prevent them from accessing a standard computer or communication device, and work-related injuries that require modification of job tasks or means to control their environment.⁴⁷

In order for clients to maximize their abilities, the Assistive Technology Assessment Center draws from a team of specialists with backgrounds in speech, physical, occupational and recreational therapy, and utilizes technical support personnel. The Assistive Technology Assessment Center is an approved evaluation site by Missouri Medicaid, the Bureau of Special Health Care Needs and Vocational Rehabilitation. Referrals are received from Independent Living Centers, Regional Centers, area schools, individual therapists, special educators, and client advocates. As a result of the evaluations performed by the Center’s Assistive Technology team, many individuals have overcome barriers in their day to day lives at home, in school, in the workplace, and in the community.⁴⁸

Missouri’s Interagency Assistive Technology Short-Term Loan Program

Missouri’s ETC Program: Equipment Technology Consortium is a short-term assistive technology equipment loan program for school districts and agencies. Agency representatives can borrow equipment on behalf of individuals with disabilities to try

out the equipment before purchasing, for use during the time equipment is in for repair, or for other short-term needs. Agencies will be able to borrow the equipment for up to six weeks.⁴⁹

Before a district or agency can borrow a piece of equipment, they must complete an agreement form that needs to be signed by an authorized district or agency representative. The agreement form must be approved prior to borrowing equipment.

Once an individual's agreement form has been approved, he/she can proceed with the equipment request. Any of the listed distribution sites can process an equipment request for up to three items. There is no limit to the number of loans. ETC has a wide range of equipment available. Categories of devices are:

- switches and mounts
- computer access
- environmental controls
- hearing devices
- home modifications
- telecommunications
- visual aids
- augmentative communication devices

Six years after it started, the ETC Program continues to experience yearly growth in the number of devices it lends and in the number of school districts and agencies who borrow from its inventory of over 1,000 assistive devices. During FY 2005, ETC lent 1,471 devices throughout the state and 450 entities signed up for the program.

Augmentative communication devices were again the devices most often borrowed, with computer adaptations and vision-related technologies comprising the second and third most borrowed types of technology. Strong consumer satisfaction continues to be a hallmark of the ETC Program with 98 percent of borrowers giving the program and its level of service strong marks.⁵⁰

There are three primary reasons that people borrow from the ETC Program. The first, and most common, is to borrow multiple items in order to compare them prior to purchase. The second reason is to borrow a loaner device when their personal device is being repaired. A third, and increasingly important reason, is to increase staff and student knowledge efforts by schools, colleges, universities and organizations.⁵¹

As more students with disabilities attend regular schools, today's educators need to know about the various devices they may encounter in their classrooms. A solid understanding of assistive technology is also a necessary skill for tomorrow's teachers, and occupational, speech and physical therapists. By tapping into the ETC inventory, local schools can conduct in-services with an array of devices present for staff to see, try and learn about. Higher education faculty can include devices in their classes to help students understand assistive technology and its specific applications for various types of disabilities. What is learned today will be applied tomorrow, exponentially increasing Missouri's assistive technology knowledge.⁵²

MoAT Assistive Technology Reimbursement Program

Funded by the Department of Elementary and Secondary Education, Division of Special Education, the AT Reimbursement Program helps school districts offset the cost of purchasing assistive technology for students with assistive technology needs written into their Individualized Education Programs (IEPs). This year, the program received 219 applications from 60 school districts throughout the state. MoAT was able to fund 111 applications, an increase over the previous year, divided among 46 different districts. The program aims to fund those forms of assistive technology between \$1,000 and \$5,000, such as Braille embossers, augmentative communication devices, computer access systems and electronic enlarging.⁵³

Missouri's school districts have taken favorably to the program. Many districts have indicated how pleased they are that this funding source is available and what an impact it has had on the students for whom they have applied. Follow-up surveying has

uncovered many instances of students being more engaged in school and achieving higher academic success.⁵⁴

TAP Program

The Telecommunications Access Program, mandated by SB721, includes the Telecommunications Access Program for Telephone (TAP-T) and Telecommunications Access Program for Internet (TAP-I). The Missouri Assistive Technology Advisory Council administers both programs. While both programs have many similarities in their administration, they are intended to provide different types of equipment.⁵⁵

For Missourians with disabilities, the two Telecommunications Access Programs (Telecommunication Access for Telephone [TAP-T] and for the Internet [TAP-I]) have made purchasing products, applying for services, searching for jobs and even attending college classes via the telephone and Internet commonplace. The TAP programs provide the adaptive telephone and computer equipment needed for basic access to telephone and Internet telecommunication for Missourians with hearing, vision, mobility and other disabilities.⁵⁶

A critical component of TAP programs is the delivery of consumer support services to assist individuals with disabilities in selecting the most appropriate adaptive equipment and to assist with installation and use of the equipment provided. TAP has provided training to staff from statewide agencies in Missouri, including the Centers for Independent Living, and Rehabilitation Services for the Blind, to assist consumers with the selection and use of the adaptive telecommunications equipment.⁵⁷

In 2006, 7,470 adaptive telephone devices were provided by TAP-T. A network of Independent Living Centers provides consumer support and helps ensure appropriate equipment matches through the use of demonstration devices. Follow-up data from program beneficiaries indicates an overall satisfaction rating of 97 percent, with most reporting they used the equipment to make emergency calls, live independently, and communicate with family and friends. Many individuals also noted that the phone allowed them to improve access to education and to get or maintain employment.

Over 43 percent of individuals reported that they had been unable to use the phone for 6-20+ years.⁵⁸

Missourians throughout the state continue to benefit from the Telecommunications Access for Internet Program. The program provided 1,327 adaptive devices a 14 percent increase in one year. The program provides adaptive technology in four broad categories: alternative keyboards and pointing devices, software adaptations, speech and Braille output, and enlargement software.⁵⁹ Though enlargement software is the most often requested adaptation, the program provided over 160 different forms of adaptive technology to consumers (during 2006).

Consumers accessing the program range in age from 2 to 95+. Individuals with vision loss make up the largest disability category to obtain services through the program. Staying in touch with family and friends and making contact with businesses and government are the primary activities users perform. Missouri is unique in that it is the only state in the nation to provide free adaptive technology for Internet access.⁶⁰

Show-Me Loans

Under 8 CSR 70 – 1.020, entitled *Assistive Technology Loan Program*, Missouri developed rules for its “Show-Me Loans.”⁶¹ During the past year, “Show-Me Loans” was able to provide \$95,984 in low-interest loans to people with disabilities to obtain assistive technology in Missouri. Loans were made to make homes more accessible, to install wheelchair lifts for vehicles, and for a variety of other cross-disability assistive technology. The program’s interest rates were among the lowest of similar programs nationally, with an average rate of 3.23 percent. The average amount borrowed during the period was \$3,479. Loan amounts ranged from \$900 to \$9,000 with an average repayment period of 39 months. The average period to process and review applications decreased from 20 days in 2003–04 to 17 days in 2004-05.⁶²

A full 70 percent of loan applications were approved during the past year. This is the case even though one-third of approved borrowers had annual incomes of \$15,000 or less, and 74 percent had yearly incomes of \$30,000 or less. During the year, borrowers

repaid a total of \$64,641 in principal and interest. Even though borrowers had relatively low incomes, far less than 1 percent (\$889) of the total amount borrowed has been defaulted since the program began. People living in every region of Missouri submitted loan applications.⁶³

3C – Employment: Wisconsin’s Medicaid Purchase Plan (MAPP)

Wisconsin’s Legislative Initiative to Create a State Medicaid Buy-In Program

Lack of access to health care is one of the most significant barriers preventing millions of Americans with disabilities from working at an income level that could cause their loss of access to Medicaid benefits. The Balanced Budget Act of 1997 and the Ticket to Work and Work Incentives Improvement Act of 1999 authorized states to enact Medicaid Buy-In Programs for workers with disabilities.

Wisconsin established its Medicaid Buy-In Program, also called the Wisconsin Medicaid Purchase Plan (MAPP), in March 2000 under the Balanced Budget Act of 1997.

Enrollment growth was modest during the program’s first year of implementation.⁶⁴

Wisconsin MAPP offers people with disabilities who are working or interested in working the opportunity to buy health care coverage through the Wisconsin Medicaid Program. Depending on an individual’s income, a premium payment may be required for this health care coverage.

To qualify for the Medicaid Purchase Plan, the following requirements must be met. The participant must:⁶⁵

- Be at least 18 years old.
- Reside in Wisconsin.
- Have individual countable assets of less than \$15,000. (Countable assets include savings, life insurance policies, stocks or bonds. A home or one vehicle is not considered a countable asset.)
- Be determined to have a disability by the Department of Health and Family Services’ Disability Determination Bureau.

- Be employed in a paid position or be enrolled in a certified Health and Employment Counseling Program.
- Have an adjusted family income of less than 250 percent of the federal poverty level based on his/her family size.

Under the Medicaid Purchase Plan, Wisconsin Statute 49.472, participants:⁶⁶

- Receive the same health benefits offered through the Wisconsin Medicaid Program.
- May earn more income than another group of Medicaid recipients without the risk of losing health care coverage.
- Are allowed increased personal and financial independence through savings opportunities, known as Independence Accounts. An Independence Account is any new financial account set up through a financial institution, such as a bank or credit union, and registered with a county/tribal human or social services department. Pre-existing retirement and pension accounts also may be used as Independence Accounts subject to similar contribution restrictions applicable to new accounts. By setting up Independence Accounts, participants can save earnings above the Medicaid Purchase Plan asset limit (\$15,000) to buy independence-related items (i.e., a home or vehicle) or services.

An Independence Account must be established after MAPP eligibility is determined. There is no limit on the amount or type of account that may be designated; however, the account must be registered with the County Economic Support Office. Deposits into Independence Accounts are exempt assets. The total deposit cannot exceed 50 percent of total gross earned income during a twelve-month MAPP review period. Retirement and pension accounts may be designated as Independence Accounts, yet, at the time of application, they will be considered countable assets.⁶⁷

Background of Wisconsin Legislation

Consumers played an instrumental role in designing the study (of barriers) and were part of a consumer-based Advisory Council for the study. Over an 18-month study

period, the researchers used focus groups and individual interviews to gather information about the employment barriers faced by people with disabilities.⁶⁸

Loss of Medicaid benefits was a major concern of the surveyed individuals, as was the lack of comprehensive vocational services, including career planning, education, and job placement. The Advisory Council made recommendations on ways to remove the identified barriers, including the recommendation of a pilot program to coordinate the various service systems (vocational, health, housing) that serve people with disabilities.⁶⁹

Building on this work, the state, along with Employment Resources, Inc. (ERI), piloted the Vocational Futures Planning Process in 1994-1995. Vocational Futures Planning involved coordination of vocational services, long term support, and rehabilitation technology services, consumer mentors and employers to develop solutions to an individual's identified barriers to employment. Based on work with an initial group of thirty participants, the process evolved into a model of individualized vocational services emphasizing benefits counseling. In 1997 and 1998, officials in Wisconsin began discussing the need for the Social Security Administration, SSI/DI, and Medicaid waivers to extend participation in employment initiatives activities.⁷⁰

In 1997, the Robert Wood Johnson Foundation, the state of Wisconsin, and Dane County jointly funded the Health Systems for Workforce Enhancement Research and Demonstration Project. Fifty-three individuals with significant physical disabilities were randomly recruited from Dane County's long-term support programs. Those assigned to the experimental group were to receive benefits and employment counseling and an assurance that their health coverage would not be taken away if they worked for wages. But project managers quickly discovered that this demonstration project would not be possible without SSA and Health Care Financing Administrative (HCFA) waivers. Instead, they conducted a feasibility project, providing counseling along with guarantees that existing benefits would be held harmless during the project period.⁷¹

Wisconsin established the *Pathways to Independence* demonstration project as a continuance of the 1997-1998 project to provide coordinated vocational and health care advising to individuals with disabilities. The state passed legislation in 1997, intending to form a program similar to a Medicaid Buy-In by using a §1115 waiver, but the passage of the Balanced Budget Act of 1997 allowed Wisconsin to add a Medicaid Buy-In as a Medicaid state plan amendment instead. In addition to general funds, the demonstration was supported by grants from the Social Security Administration and the Robert Wood Johnson Foundation.⁷²

Role of the Wisconsin Executive Branch

The Wisconsin executive branch took a strong leadership role in the development of the Medicaid Buy-In Program, based on consumer input and previous efforts to redesign delivery systems for children, elders and people with disabilities.⁷³

The Medicaid Buy-In Program was developed and implemented by the various departments and bureaus of the Medicaid agency, including the HCBS division, the Medicaid eligibility division and the aging/long term care division. The Wisconsin Department of Workforce Development's Division of Vocational Rehabilitation collaborates and offers feedback in an advisory capacity through the Pathways Program. To maximize effective implementation, the premium collection, outreach and eligibility worker training sessions were incorporated into existing processes and administrative structures within the Department of Vocational Rehabilitation.⁷⁴

The Pathways program is run jointly by the Medicaid agency, the Department of Workforce Development and the Office of the Governor. The Medicaid agency largely serves as the program administrator, the Department of Workforce Development serves as rehabilitative services administrator and the Office of Governor provides additional support. Employment Resources, Inc. is under contract to provide benefits counseling. The Bureau of Community Mental Health (BCMh), Department of Public Health (DPH), and the Bureau of Developmental Disabilities Services (BDDS) also provide technical assistance at local sites.⁷⁵

Effects of the Medicaid Buy-In Program for Wisconsin Participants

Wisconsin provides an incentive for continued work effort by providing Medicaid Buy-In Program coverage during temporary periods of unemployment and before an individual finds a job. Wisconsin calculates separate payment obligations for earned and unearned income with proportionately smaller premiums assessed on income derived from work. For people liable for premiums, Wisconsin deducts the SSI income standard, Impairment Related Work Expenses (IRWE), and medical and remedial expenses, and then collects the remainder of the unearned income as part of the premium. The individual pays 3 percent of his or her earned income, in increments of \$25, as a premium.⁷⁶

In Wisconsin, if a Medicaid Buy-In Program participant has been in the program for at least six months and has a health setback that makes him or her unable to work, the work requirement may be exempted for up to 6 months. The individual may also participate in the Health and Counseling Program for up to a year. However, individuals may only participate in the Health and Counseling Program twice in a two-year period with at least six months between each period of participation.⁷⁷

Wisconsin calculates premium liability by comparing the individual's monthly income to the family income limit. If the participant's gross individual monthly income is less than 150 percent of the Federal Poverty Level (FPL) for the family size of which the beneficiary is a member, there is no premium obligation. For example, an individual in the Medicaid Buy-In with a family of three will pay a premium only if his or her individual income (earned and unearned) is at least \$1,769 per month (150 percent of the FPL for a family of three).⁷⁸

The premium has two parts. The first component affects unearned income. An individual pays 100 percent of his unearned income, minus a standard living allowance (\$635/month in 2001), Impairment-Related Work Expenses and medical and remedial expenses. The second component of the premium is 3 percent of the individual's

earned income. If unearned income deductions exceed actual unearned income, the difference is subtracted from earned income before assessing the 3 percent premium.⁷⁹

If Medicaid Buy-In participation is terminated because of failure to pay the premium, the enrollee must wait at least 6 months before reapplying and he or she will owe any unpaid premiums from the prior eligibility period. If the enrollee waits at least 12 months before reapplying, he or she may do so without repayment of past unpaid premiums. Premiums may be paid up to 12 months in advance or until the time of the next reapplication. Under Wisconsin's Health Insurance Premium Payment Program, Medicaid may pay for insurance coverage for any individual eligible for Medicaid through his/her (or the spouse's) employer's health plan if doing so would cost less than Medicaid. People in the Medicaid Buy-In Program would pay the MAPP premium, and Wisconsin Medicaid would pay the insurance premium and cost-sharing expenses, such as co-payments. If a Medicaid Buy-In participant loses employment, he or she does not automatically lose Medicaid Buy-In eligibility.⁸⁰

Wisconsin has sought two waivers from the Social Security Administration to provide income protections to people with disabilities. The SSI waiver, granted in January 2001, allows SSI recipients to count \$1 of every \$4 of wages as income, rather than \$1 of every \$2 as required by current law. The waiver also allows the state to increase the SSI assets limit from the current \$2,000 to 50 percent of earnings (not to exceed \$8,000). The waiver also eliminates disability reviews for people with permanent disabilities. In addition, certain types of unearned income—private disability insurance, workers compensation, and unemployment insurance—will be counted as earned income for the purposes of calculating the SSI cash benefit. The SSDI waiver request proposes a \$1 for \$4 reduction in SSDI benefits from earnings, rather than the current dollar-for-dollar benefit reduction. The waiver also proposes “stop the clock” provisions for the Trial Work Period, extended periods of eligibility, and continued Medicaid coverage. Disability reviews would be suspended unless medical improvement is expected. The SSDI waiver was submitted in June 2000.⁸¹

In the calculation of unearned income premiums, Wisconsin's Medicaid Buy-In Program uses the state SSI supplementation program benefit standard for "living independently" as its base. People with gross incomes at or above 150 percent of the FPL can retain a total of \$635 of monthly unearned income (an amount equal to the federal SSI payment plus the state SSI supplementation program plus \$20). Any remaining unearned income is then returned to the state as a portion of the Medicaid Buy-In premium.⁸²

Wisconsin uses a work incentive provision from the SSI Program to increase the income level for Medicaid eligibility under the Medicaid Buy-In. To encourage employment, Wisconsin deducts Impairment-Related Work Expenses from the amount of an individual's countable income. A similar deduction is made when calculating the amount of unearned income to be paid as a premium. This is, in effect, an individualized budgeting approach that increases both the income eligibility standard and the maintenance allowance for an individual with work expenses. Enrollment in the Medicaid Buy-In numbered 1,590 people as of July 2001. According to state data, approximately 10 percent of participants have earned income exceeding the \$740 Substantial Gainful Activity earnings test.⁸³ As of March 31, 2005, Wisconsin Medicaid Buy-In Program participation rose to 8,265 people.⁸⁴

3D – Transportation: Maryland's Statewide Special Transportation Assistance Program

Maryland's Statewide Special Transportation Assistance Program (SSTAP) is an example of an effective approach to the transit and paratransit needs of individuals with disabilities. In many areas across Maryland, jobs and job seekers are far apart, often crossing county and city lines. This gap is even wider for low-income people. In addition, many companies across the state face a shortage of workers, especially entry-level employees.⁸⁵

With this in mind the Maryland Mass Transit Administration (MTA), in conjunction with Governor Glendenning's Coordinating Committee for Human Services Transportation, worked with local jurisdictions to develop Maryland's Job Access and Reverse Commute Program. This program has allowed the state to develop transportation

services to meet local community needs and link workers with job opportunities. A map describing projects funded through the state's Job Access and Reverse Commute Program is available.⁸⁶

Maryland received \$5.1 million in federal funds over the first two years of the Job Access Program, and will receive \$2.4 million in year three. The Maryland Department of Human Resources (DHR) and the MTA work closely on the Job Access Program, with DHR providing significant funding to meet the matching requirement of the federal program. The Job Access and Reverse Commute Program also has resulted in improved collaboration among local transit providers and human services agencies and a more coordinated effort to connect people with jobs.⁸⁷

In addition, the State began looking to ensure that the Job Access Program could be sustained beyond the five-year federal authorization. This legislation was modeled after Maryland's Statewide Special Transportation Assistance Program (SSTAP) that funds general-purpose transportation services for the elderly and People with disabilities. The Job Access bill passed the Maryland House of Delegates, but was not acted on by the Maryland Senate.⁸⁸

An example of how the SSTAP Program is administered at the local level in Maryland is St. Mary's County. The St. Mary's Transit System (STS), based in California, Maryland, provides public and specialized transportation services in St. Mary's County. STS began operating the SSTAP services differently. Before the onset of the service change, STS made extensive efforts to publicize the change to customers and health care providers. Under a new approach, a different geographic area of the county, or zone, is served each day of the week. For example, on Mondays, the area south of Lexington Park is served, on Tuesdays service is provided in the north end of the county, and so forth.⁸⁹

In addition, STS worked with health care providers to encourage them to schedule appointments with SSTAP customers on the day of the week served by STS between 8 a.m. and 5 p.m. The SSTAP route serves a percentage of the dialysis trips equally with ADA paratransit; SSTAP has approximately 624 dialysis trips a year. As a result,

SSTAP passenger trips are more effectively coordinated. Typical trips involve two or three customers sharing a ride, and many customers have indicated that they enjoy the social nature of the trip.⁹⁰

In terms of measurable efficiency and productivity improvements, management is continuing to monitor service performance statistics for the new service approach, and fine-tune the service.

For example, one modification made after the first few months of monitoring operations was to serve the entire county on Thursdays, since demand was low for the geographic zone originally assigned to Thursdays. In addition to the new scheduling approach, STS has instituted several other changes to reduce inefficiencies, including requiring “no-shows” to pay the regular fare for the missed trip (\$3 per one-way trip), which has reduced the number of no-shows. The new no-show policy also requires customers who have missed two trips to call in to confirm that they will be riding subsequent trips. STS also has begun issuing confirmation numbers each time a trip is scheduled, which makes it easier for scheduling and dispatching staff to find specific trips whenever a customer calls. SSTAP trip reservations are accepted up to 30 days in advance. STS uses Excel and Access to schedule trips and maintain their database of approximately 900 SSTAP customers, for which 17,000 trips per year are provided. STS also implemented a formal customer application process, which has been helpful in maintaining the customer database, and began issuing identification cards. STS hopes to purchase an updated routing system in the future.⁹¹

People with disabilities will use an array of transportation options to access destinations enjoyed by their peers without disabilities. The Maryland Department of Disabilities (MDOD) explains that the goal is to create reliable, cost-effective transportation enabling people with disabilities to access destinations of their choosing at the same rate as their peers without disabilities. This way, people with disabilities will have improved confidence in the MDOT paratransit system.⁹²

MTA, in conjunction with the Citizen's Advisory Committee on Accessible Transportation (CACAT), will continue the training protocol for all MTA and Mobility personnel that will be conducted by consumers who use the paratransit system. MTA will continue to identify intersections of opportunity within agency planning exercises and procurement development to solicit input from the CACAT Committee. MDOD and MTA will consult with the members of CACAT, individuals with disabilities and representative organizations regarding ways in which to strengthen CACAT's effectiveness, as well as continue to monitor MDOT's on-time goal of 95 percent for paratransit trips.⁹³

MDOD's plan included that by December 31, 2006, MTA would develop a reporting and monitoring process among stakeholders that includes performance criteria, Federal Transit Administration trends, and consumer feedback in the provision of paratransit services. MTA would extend the process of Taxi Access certification to include all certified paratransit users. MTA would expand the number of Taxi Access sub-contractors, to include providers of taxi service to the users of wheelchairs. The goal was to increase the use by people with disabilities of fixed-route transportation in greater numbers.⁹⁴

On December 31, 2005, 100 percent of MTA buses would be fully accessible (e.g., low floored, Clever Devices) to enable a greater number of people to ride fixed routes. MTA will ensure compliance with procurement timelines to keep the acquisition of fully accessible vehicles on schedule. By December 31, 2006, MDOD would examine the feasibility of uniform standards to assess paratransit certification to be used by physicians to also include an assessment of whether or not travel training could allow an individual to ride fixed route.⁹⁵

By July 1, 2006, MDOD planned to convene a group of stakeholders to review the paratransit certification standards and ultimately, recommend ways in which the standards can be modified to enhance independence on the part of users. The group also should recommend ways to increase the availability and types of travel training provided. By July 1, 2006, MDOD would examine the technical feasibility, cost

feasibility, and schedule feasibility of providing cross-regional transportation capacity in both the fixed route and paratransit systems to enable people with disabilities to travel across regions using different systems. People with disabilities who rely on provider-run transportation to get to a human service program (DDA, MHA, DOA, etc.) would experience shorter trips, increased flexibility, and streamlined scheduling.⁹⁶

3E – Housing: Kentucky’s Universal Design Program Kentucky’s Adoption of Universal Design Principles

Kentucky uses financial incentives to encourage the adoption of universal design principles in the building of affordable housing. In Kentucky, builders and developers whose rental housing and/or single-family home construction or rehabilitation projects are partially (50 percent) or wholly financed by the Kentucky Housing Corporation (KHC), must follow KHC’s Universal Design Policy. This policy, in effect since 2003, is designed to “ensure that much of the housing produced with KHC financing meets the needs of the greatest number of people for the longest period of time.”⁹⁷

Universal design is a concept used to achieve a number of goals. Universally designed homes allow homeowners to stay in their homes as they age because these homes are already adapted for possible changing physical needs. Universal design helps minimize or avoid the high cost of renovations and additions that may be required to meet changing physical needs. Universal design allows the greatest number of individual needs to be met – whether a guest or relative uses a wheelchair or the homeowner is experiencing a short-term loss of physical ability.⁹⁸

In 2001, Kentucky was awarded a Real Choice Systems Change Grant for Community Living from the Centers for Medicare and Medicaid Services (CMS). The purpose of this grant is to enable children and adults who have a disability or long-term illness to:

- Live in the most integrated community setting appropriate to their individual support requirements and preferences

- Exercise meaningful choices about their living environment, the providers of services they receive, the types of supports they use, and the manner by which services are provided
- Obtain quality services as consistent as possible with their community living preferences⁹⁹

With support from the CMS Real Choice grant and input from the public through public hearings and partners across the state, the Department of Design and Construction Review of the Kentucky Housing Corporation developed a *Universal Design Handbook* for use by builders and developers in the construction and reconstruction of affordable housing. The Universal Design Policy went into effect on January 1, 2003.¹⁰⁰

While housing that incorporates universal design can clearly benefit people with disabilities, the Department of Design and Construction Review's definition of universal design does not target any group in particular. In fact, their definition is all-inclusive and stresses the wide-ranging and lifelong benefits of housing built according to universal design principles. Universal design is a building concept that incorporates products, general design layouts, and characteristics into residences in order to:

- Make the residence usable by the greatest number of people
- Respond to the changing needs of the resident
- Improve marketability of the residence

The *Universal Design Handbook* prescribes the following design guidelines:

1. Finished hallways should be 42" wide.
2. All doorways, including closet doors and entry doors, should be 32" wide at minimum. Specifications for entry platforms also are included.
3. Ground level and elevator-accessible units must have a minimum of one full universally designed bathroom.

4. Single lever or ADA-approved faucets must be installed at all sinks, showers, and tubs.
5. Electrical outlets have to be installed at a minimum height of 15” and light switches, fan switches and thermostats at a maximum height of 48.”
6. All units must have at least one universally designed bedroom on the ground level or elevator accessible floor.

Specific actions for exterior accessibility, including parking areas and walkways, also are included and, as an acknowledgement of the fact that more and more members of the population own and regularly use personal computers, cabling for high-speed Internet access also is required.

Universal Design Funding Resources

There are several ways that universal guidelines are promoted at the federal, state, and local levels. Federal regulations, for example, set accessibility standards for large new or rehabilitated multifamily housing built with the help of federal funds, but not for smaller projects. Some states, such as Georgia, and cities, such as Irvine, CA, have developed their own accessibility guidelines that builders and developers may voluntarily adopt, although these guidelines apply mostly to privately funded projects. In Kentucky, the KHC has tied its universal design policy to its housing finance programs. Thus, as mentioned above, KHC universal design requirements are mandatory for any projects that receive debt or subsidy financing from KHC equal to 50 percent or more of the total cost for new construction (or reconstruction) of single-family or multi-family housing. The Department of Design and Construction Review offers a full array of technical assistance, and likes to begin working with developers from the inception of the project to ensure that they are meeting all building requirements, including the universal design guidelines. Once the project is built, the Department's inspectors inspect the buildings and certify them.

Many developers and builders around the country have been reluctant to incorporate universal design features into their projects because they believe the cost is prohibitive.

Consumers who buy new homes also are reluctant to request the features because they fear these features will add substantially to the cost of the housing. But several studies have shown that the added cost of universal design features is very modest.¹⁰¹ In Kentucky, KHC's Department of Design and Construction Review has polled developers of multi-family and single-family dwellings and has found that, as a result of Universal Design Policy, additional building costs for a two-bedroom unit are between \$900 and \$1,500.¹⁰² "Retrofitting," or renovating homes after they are built to accommodate the occupants' changing physical needs, is considerably more expensive.

According to the Department of Design and Construction Review, since the Universal Design Policy went into effect in 2003, at least 500 units have been built that meet universal design requirements.

Kentucky Success Stories

Housing corporations around the U.S. have given thousands of Americans access to affordable housing. In the past 31 years, KHC has helped many families find affordable rental housing, and its homeownership programs have assisted over 55,000 families in becoming homeowners, making Kentucky's homeownership rate (74 percent) considerably higher than the overall national rate of 67.8 percent, according to 2001 U.S. Census data.¹⁰³ Whether they own or rent, not only do more people have access to affordable housing, with KHC's Universal Design Policy in full effect, they will have housing that will meet their needs for a long time to come. The following are examples of recent projects built according to the Universal Design Policy Guidelines.

Hilton and Lively Partnership is a builder of affordable housing in central and western Kentucky, and many of their clients are single parents, elders, and people with disabilities. Hilton and Lively receives some financing through KHC, so it has to comply with KHC's Universal Design Policy. The firm works with manufactured housing, which does not normally incorporate universal design principles, such as wider hallways, generous space in bathrooms, and so on. But it has found a housing manufacturer willing to revise its construction plans to meet the universal design requirements and the

firm is standing behind the quality of the homes they build by providing warranties, construction reinforcements, a traditional-looking roof pitch, a permanent foundation, and higher insulation standards compared to other similar homes.

Since 1998, Hilton and Lively has been helping provide affordable, quality homes in the central and western parts of the state. Lively receives some financing through KHC, which requires homes that include at least 50 percent of KHC financing to meet the universal design standards. “Not many developers are wanting to do the type of building we do,” said Lively. “We’ve always focused on affordable houses. We just see a great need. Many of our clients are single parents, elders and people with disabilities. We often receive referrals from USDA Rural Development and other service organizations.” It took some effort for Hilton and Lively to find a housing manufacturer willing to revise their construction plans to meet the universal design requirements, said Lively.¹⁰⁴

In spite of the some assumptions about manufactured homes, Hilton and Lively's products have been described as high quality and are among the first in the state to meet KHC's universal design requirements.

Hilton and Lively's most recently funded project, the Hilton and Lively Homeownership Program, will assist families in finding affordable housing in Big Clifty. The project received KHC financing through the Home Investment Partnerships Program (HOME) Program and the Housing Development Fund. Hilton and Lively's service area includes Grayson, Hardin, LaRue, Hart, Ohio and Breckinridge counties.¹⁰⁵

Another project built with funds from the HOME Investment Partnerships Program is the South Main Street Apartments in Edmonton, Kentucky, which will serve older people with incomes at or below 50 percent of the average median annual income for the area, which is currently \$32,500. Funds from the state's Small Multi-Family Affordable Loan Program (SMAL) also were used to build the one-story, 11-unit complex. Through its Universal Design standards policy, KHC is helping to ensure the quality, affordability and sustainability of homes across the state. Lynn Luallen, KHC's chief executive

officer, said, “The families that obtain universally designed homes will benefit today and in years to come because of the standards and sustainability they provide.”¹⁰⁶

Created by Congress in 1990, HOME provides funding for various types of affordable housing production and rehabilitation. KHC awards HOME funding to successful applicants, such as local governments, housing authorities, private developers, and non-profit housing developers. KHC administers and monitors the HOME Program for the U.S. Department of Housing and Urban Development.¹⁰⁷

Kentucky is among a handful of states in the nation to fully embrace the variety of activities available under the HOME Program, enabling KHC and the agencies it funds to do a variety of activities, including homeowner rehabilitation, home buyer assistance, rental projection projects and tenant-based rental assistance.¹⁰⁸

Seven architects and design professionals from Kentucky, New York and California were winners of the KHC Universal Design Competition – *Visions for a New Kentucky Home*. A jury of five architectural and housing industry professionals named the winners based on criteria ranging from meeting KHC’s universal design standards to square footage, cost and general presentation requirements.

In January 2005, the KHC Board of Directors announced the allocation of \$430,750 from the Affordable Housing Trust Fund (AHTF) to four projects throughout Kentucky. These projects will conform to KHC’s Universal Design policies. The following recipients were listed for funding:¹⁰⁹

Recipient	Counties Served	Population Served	Amount
Lexington Habitat for Humanity	Fayette	Families with children, single parents	\$100,000
Habitat for Humanity of Owensboro/Daviess County, Inc.	Daviess	Families with children, single parents	\$78,750
Frontier Housing, Inc.	Magoffin, Menifee, Morgan, Wolfe	Elderly, families with children, single parents, individuals with physical disabilities, and/or homeless	\$210,000
Mountain Comprehensive Care Center, Inc.	Floyd, Johnson, Magoffin, Martin, Pike	Individuals with intellectual disabilities	\$42,000

The AHTF was established in 1992 by the Kentucky State Legislature to address the critical housing needs of very low-income Kentuckians, including the people with mental health, intellectual and physical disabilities and people on the verge of homelessness. The fund supports projects that assist people at or below 60 percent of the area median income with a preference to help people at or below 30 percent of the area median income. To date, nearly \$31,000,000 has been allocated from AHTF. What's more, AHTF funds have stimulated additional investments of more than \$168,000,000 from other sources. Since its inception, AHTF has financed the production of 4,865 homes or housing units for low-income and special needs Kentuckians.¹¹⁰

Since 1992, funding sources for AHTF have included the state's General Fund, Kentucky Health Services Cabinet, KHC and the Kentucky Lottery. Nearly 80 percent of the AHTF's total funding came from a portion of the Kentucky Lottery's unclaimed prize winnings. However, authorization for this resource expired June 30, 2003. For fiscal

year 2003-04, the Kentucky General Assembly allocated \$3,000,000 to replace the lost lottery funding. Governor Fletcher included \$2,500,000 for the fund in the Fiscal Year 2005 Spending Plan. Affordable housing advocates continue to seek a permanent funding source for AHTF.¹¹¹

3F – Asset Development: Washington’s Individual Development Accounts: The Washington Statute and Program

Matched Savings Plans such as Individual Development Accounts (IDAs) are an emerging strategy for a growing number of states to support low-income wage earners and families to improve their economic status and escape poverty. IDAs were introduced by Michael Sherradan in 1988, who suggested that: “[1] saving and asset accumulation are largely a matter of structures and incentives, not merely personal preferences, and [2] assets may have a wide range of positive psychological, social, and economic impacts including deferred consumption.”¹¹²

Low-income participants’ savings contributions must come from income they have earned. The state provides \$2 for every \$1 saved by the participant, up to a maximum match of \$4,000 per participant (i.e., \$2,000 savings + \$4,000 match = \$6,000 total). The state’s match is available for three years after the participant opens the account. Participants must attend financial skills-building classes to be eligible for the state’s match.¹¹³

Eligibility

Families who are eligible to receive assistance under Temporary Assistance for Needy Families (TANF), and families that have received TANF assistance in the past and whose incomes are less than 175 percent of federal poverty level, qualify to open an account. Families do not have to meet TANF eligibility criteria at the time their IDA funds are used.¹¹⁴

When an individual beneficiary of SSI exceeds \$2,000 in assets or a married couple exceeds \$3,000, SSI benefits are jeopardized. The IDA savings, not including the match, are counted against these resource limits. Social Security reform to exclude

IDAs from resource consideration will be essential to open up participation to the broad disability community.

The cornerstone of IDAs is that earned income is necessary as a basic eligibility requirement. Beneficiaries of SSI and recipients of Social Security Disability Insurance (SSDI) who are not working but who would benefit through IDA participation are excluded from participation. For IDAs to be truly accessible there needs to be an allowance in federal IDA legislation for people with disabilities to apply their SSI or SSDI funds to their savings.

Administrative Structure

The state contracts with community-based organizations (CBO) using a competitive process. These CBOs recruit and enroll participants, and provide financial skills-building classes, individual counseling, and account management. CBOs that lack expertise in homeownership, higher education, or business start-up may partner with other organizations that can help participants invest responsibly in those assets. CBOs also partner with local financial institutions to hold the participants' deposits and restrict withdrawals. The participant's match is held in "trust" until the participant is ready to apply the funds to an eligible use. Match funds are paid directly to the person or institution from which the asset is being acquired, not to the participant. For example, the funds would be paid directly to the educational institution or the seller of a house the participant is buying. Regular statements are issued to participants showing how much money is in their account. Participants are allowed to invest their contribution in any way allowed by the partner financial institution. The state matches 2-to-1 the amount at the time the participant is ready to apply his or her IDA funds to an eligible use. Any losses of the principal are borne by the participant. Participants are allowed to withdraw their own contributions for purposes other than home ownership, higher education, or business start-up, but they lose the state's match if they do so. Specific provisions allow for a temporary 'leave of absence' from the program or withdrawal of funds due to an emergency.¹¹⁵

Funding

Funding for the IDA Program is currently from the state's Temporary Assistance for Needy Families (TANF) reinvestment funds. A total of \$3 million has been awarded to date, but no additional funds are anticipated. An estimated 567 accounts have been established by existing IDA providers. IDA contractors currently serve individuals in over a dozen counties.¹¹⁶

Statute

In 2005, Washington passed statute 43.31.460 entitled, SEED act—Individual Development Accounts Program—Rules,¹¹⁷ updating the IDA law, which states in pertinent part:

(2) An individual development account may be established by or on behalf of an eligible low-income individual to enable the individual to accumulate funds for the following purposes:

- (a) The acquisition of postsecondary education or job training;
- (b) The purchase of a primary residence, including any usual or reasonable settlement, financing, or other closing costs;
- (c) The purchase of a computer, an automobile, or home improvements; or
- (d) The purchase of assistive technologies that will allow a person with a disability to participate in work-related activities.¹¹⁸

Senate Bill Report 5469 states that the appropriation for this bill is \$3,000,000 for the biennium ending June 30, 2007.¹¹⁹

Legislative History

The movement for IDAs in Washington began under the Washington WorkFirst Act of 1997, where recipients of Temporary Assistance for Needy Families (TANF) were permitted to establish IDAs with earned income.¹²⁰ The Department of Social and Health Services is directed to fund an IDA Program as well, under statutory provision RCW 74.08A.220. During the interim between the 1999 and 2000 legislative sessions, state staff researched potential design and implementation issues for a Washington

state-supported IDA Program for TANF recipients. Their tasks included determining the actions and resources that would be needed to establish IDA programs, as well as the barriers that might hinder such programs. Research was completed on this project with the help of a coalition of community-based organizations and other interested parties. The coalition was facilitated by the Community, Trade, and Economic Development Department – whose successor, the Office of Trade and Economic Development (OTED), is the department under which the program now runs.¹²¹

The state approved the use of \$1.8 million per year in TANF reinvestment funds for matching dollars and administration costs for IDA programs. It is providing a 2-to-1 match for the first three years after a participant opens an account. Community-based organizations (CBOs) with whom contracts would be possible were responsible for recruiting and enrolling participants, and for providing financial skills-building classes, individual counseling, and account management. CBOs also were required to partner with local financial institutions to hold participants' accounts.¹²²

Item 4 – Appendix D: Examples of State Legislation on Financial Incentives

Louisiana

The final version of HR 1836 includes the following additional enhancements to Louisiana’s START Savings Program and to other qualified state-sponsored tuition programs:

1. Expands the amount of room and board expenses that may be paid from a qualified tuition program.
2. Provides for transfers of credits, or “rollovers,” from one qualified tuition program to another qualified tuition program for the benefit of the beneficiary, limiting such rollovers to one per 12-month period.
3. Revises the definition of “member of family” to include first cousins.
4. Modifies the definition of qualified higher education expenses to include expenses of a special needs beneficiary that are necessary in connection with his or her enrollment or attendance at the eligible education institution.

Missouri

SB721 In Its Entirety:

This act revises programs for the handicapped to enhance access to telecommunications, to enable access to other assistive technologies and to provide for blind screening and education.

TELECOMMUNICATIONS EQUIPMENT PROGRAM - The act revises the program for telecommunications equipment for the hearing and speech-impaired. The act adds definitions to expand the scope of the program to all telecommunications equipment, including voice and text.

The Missouri Assistive Technology Advisory Council, as the program administrator, will provide a statewide telecommunications equipment and

distribution program for people who cannot use traditional equipment due to disability.

The act specifies qualifications of the program administrator which include appropriate expertise and experience to provide oversight, customer service and accountability. Expenditures for program administration will not exceed 20 percent of total program expenses. The Missouri Assistive Technology Advisory Council may enter into contracts to deliver consumer support and administrative services relating to equipment distribution.

The Public Service Commission will annually request, as a separate budget item, appropriations from the deaf relay service and equipment distribution program fund to deliver dual-party relay service. The Missouri Assistive Technology Advisory Council will annually request, through a separate line item, an appropriation from the same fund to deliver the telecommunications equipment distribution program.

The Deaf Relay Service and Equipment Fund surcharge will not be increased for 2 years, subject to changes in federal requirements. After 2 years, the Council will annually adjust the Fund surcharge based upon the Department of Labor and Industrial Relations' recommendation. The act requires means testing to allocate services efficiently.

ASSISTIVE TECHNOLOGY LOANS - The act requires the Missouri Assistive Technology Council to establish an Assistive Technology Loan Program.

The Council shall spend available moneys in four equal shares each quarter to ensure that the loan program will provide loans throughout the entire fiscal year. The act creates the "Assistive Technology Loan Revolving Fund," which shall be used to fund the Assistive Technology Loan Program.

The interest rates for loans shall be lower than comparable commercial lending rates and shall be established by the Council based on the borrower's ability to

pay. Loans may be made with no interest. Loan repayment periods shall not exceed ten years. The Council shall promulgate rules to implement the program and file annual reports with the Governor and General Assembly. This portion of the act is contained in SB 935 (2000).

BLIND ASSISTANCE PROGRAM - The Blind Education, Screening and Treatment Program Fund is created. Applicants for registration of motor vehicles and applicants for a license may donate one dollar to the fund. Moneys in the fund may be used to provide eye screenings and treatment to prevent blindness.

Wisconsin

S. 49.472 Medical assistance purchase plan.

(1) Definitions. In this section:

(a) "Earned income" has the meaning given in 42 USC 1382a (a) (1).

[a] "Family" means an individual, the individual's spouse and any dependent child, as defined in

[http://nxt.legis.state.wi.us/nxt/gateway.dll?f=templates&fn=default.htm&vid=Wl:Ddefault&d=stats&jd=19.42\(7\)#JUMPDEST_19.42\(7\)](http://nxt.legis.state.wi.us/nxt/gateway.dll?f=templates&fn=default.htm&vid=Wl:Ddefault&d=stats&jd=19.42(7)#JUMPDEST_19.42(7))

(b) "Health insurance" means surgical, medical, hospital, major medical or other health service coverage, including a self-insured health plan, but does not include hospital indemnity policies or ancillary coverage such as income continuation, loss of time or accident benefits.

(c) "Independence account" means an account approved by the department that consists solely of savings, and dividends or other gains derived from those savings, from income earned from paid employment after the initial date on which an individual began receiving medical assistance under this section.

(d) "Medical assistance purchase plan" means medical assistance, eligibility for which is determined under this section.

(e) "Unearned income" has the meaning given in 42 USC 1382a (a) (2).

(2) Waivers and amendments. The department shall submit to the federal Department of Health and Human Services an amendment to the state medical assistance plan, and shall request any necessary waivers from the secretary of the federal Department of Health and Human Services, to permit the department to expand medical assistance eligibility as provided in this section. If the state plan amendment and all necessary waivers are approved and in effect, the department shall implement the medical assistance eligibility expansion under this section not later than January 1, 2000, or 3 months after full federal approval, whichever is later.

(3) Eligibility. Except as provided in [\(a\) The individual's family's net income is less than 250 percent of the poverty line for a family the size of the individual's family. In calculating the net income, the department shall apply all of the exclusions specified under 42 USC 1382a \(b\).](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%286%29%28a%29&softpage=Document - JUMPDEST 49.472(6)(a)sub. (6) (a), an individual is eligible for and shall receive medical assistance under this section if all of the following conditions are met:</p></div><div data-bbox=)

(b) The individual's assets do not exceed \$15,000. In determining assets, the department may not include assets that are excluded from the resource calculation under 42 USC 1382b (a) or assets accumulated in an independence

account. The department may exclude, in whole or in part, the value of a vehicle used by the individual for transportation to paid employment.

(c) The individual would be eligible for supplemental security income for purposes of receiving medical assistance but for evidence of work, attainment of the substantial gainful activity level, earned income and unearned income in excess of the limit established under 42 USC 1396d (q) (2) (B) and (D).

(d) The individual is legally able to work in all employment settings without a permit under [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=103.70&softpage=Document - JUMPDEST 103.70](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=103.70&softpage=Document-JUMPDEST_103.70)s. 103.70.

(e) The individual maintains premium payments calculated by the department in accordance with [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29&softpage=Document - JUMPDEST 49.472\(4\)](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29&softpage=Document-JUMPDEST_49.472(4))sub. (4), unless the individual is exempted from premium payments under [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29%28b%29&softpage=Document - JUMPDEST 49.472\(4\)\(b\)](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29%28b%29&softpage=Document-JUMPDEST_49.472(4)(b))sub. (4) (b) or [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%285%29&softpage=Document - JUMPDEST 49.472\(5\)](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%285%29&softpage=Document-JUMPDEST_49.472(5))(5).

(f) The individual is engaged in gainful employment or is participating in a program that is certified by the department to provide health and employment services that are aimed at helping the individual achieve employment goals.

(g) The individual meets all other requirements established by the department by rule.

(4) Premiums.

(a) Except as provided in [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29%28b%29&softpage=Document - JUMPDEST 49.472\(4\)\(b\)par. \(b\) and](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29%28b%29&softpage=Document - JUMPDEST 49.472(4)(b)par. (b) and) [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%285%29&softpage=Document - JUMPDEST 49.472\(5\)sub. \(5\),](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%285%29&softpage=Document - JUMPDEST 49.472(5)sub. (5), an individual who is) an individual who is eligible for medical assistance under [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%283%29&softpage=Document - JUMPDEST 49.472\(3\)sub. \(3\) and](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%283%29&softpage=Document - JUMPDEST 49.472(3)sub. (3) and receives medical) receives medical assistance shall pay a monthly premium to the department. The department shall establish the monthly premiums by rule in accordance with the following guidelines:

1. The premium for any individual may not exceed the sum of the following:

a. Three and one-half percent of the individual's earned income after the disregards specified in [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29%28a%292m.&softpage=Document - JUMPDEST 49.472\(4\)\(a\)2m.subd. 2m.](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29%28a%292m.&softpage=Document - JUMPDEST 49.472(4)(a)2m.subd. 2m.)

b. One hundred percent of the individual's unearned income after the deductions specified in [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29%28a%292.&softpage=Document - JUMPDEST 49.472\(4\)\(a\)2.subd. 2.](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29%28a%292.&softpage=Document - JUMPDEST 49.472(4)(a)2.subd. 2.)

2. In determining an individual's unearned income under http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29

[%28a%291.&softpage=Document - JUMPDEST 49.472\(4\)\(a\)1.subd. 1.](#), the department shall disregard all of the following:

a. A maintenance allowance established by the department by rule. The maintenance allowance may not be less than the sum of \$20, the federal supplemental security income payment level determined under 42 USC 1382 (b) and the state supplemental payment determined under [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.77%282m%29&softpage=Document - JUMPDEST 49.77\(2m\)s. 49.77 \(2m\).](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.77%282m%29&softpage=Document - JUMPDEST 49.77(2m)s. 49.77 (2m).)

b. Medical and remedial expenses and Impairment-Related Work Expenses.

2m. If the disregards under [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29%28a%292.&softpage=Document - JUMPDEST 49.472\(4\)\(a\)2.subd. 2.](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29%28a%292.&softpage=Document - JUMPDEST 49.472(4)(a)2.subd. 2.) exceed the unearned income against which they are applied, the department shall disregard the remainder in calculating the individual's earned income.

3. The department may reduce the premium by 25 percent for an individual who is covered by private health insurance.

(b) The department may waive monthly premiums that are calculated to be below \$10 per month. The department may not assess a monthly premium for any individual whose income level, after adding the individual's earned income and unearned income, is below 150 percent of the poverty line.

(5) Community options participants. From the appropriation under [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=20.435%287%29%28bd%29&softpage=Document - JUMPDEST 20.435\(7\)\(bd\)s. 20.435 \(7\) \(bd\),](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=20.435%287%29%28bd%29&softpage=Document - JUMPDEST 20.435(7)(bd)s. 20.435 (7) (bd),)

the department may pay all or a portion of the monthly premium calculated under [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29%28a%29&softpage=Document - JUMPDEST 49.472\(4\)\(a\)sub. \(4\) \(a\)](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=49.472%284%29%28a%29&softpage=Document - JUMPDEST 49.472(4)(a)sub. (4) (a)) for an individual who is a participant in the community options program under [http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=46.27%2811%29&softpage=Document - JUMPDEST 46.27\(11\)s. 46.27 \(11\)](http://folio.legis.state.wi.us/cgi-bin/om_isapi.dll?clientID=15953720&infobase=stats.nfo&jump=46.27%2811%29&softpage=Document - JUMPDEST 46.27(11)s. 46.27 (11)).

(6) Insured persons.

Maryland

The Fiscal Note for House Bill 758 states in pertinent part:

MTA has a specialized, shared-ride, curb-to-curb service for people with disabilities who are not able to ride fixed-route public transportation. Paratransit service is provided within three-quarters of a mile of any fixed-route service (bus, light rail, or subway) in Baltimore City and Baltimore and Anne Arundel counties. To be eligible for Paratransit, individuals must provide a physician's statement that confirms their physical disability. MTA then evaluates the individuals to determine which ones meet the criteria for the specialized service, which charges a \$1.55 one-way fare. The estimated cost to the State is \$22.96 per passenger.

The intent of the legislation was that the Transportation Trust Fund expenditures would increase by \$400,000 annually, beginning in fiscal 2004, to provide grants required by the bill. MTA can administer the program with existing resources. Approximately 508,000 people would qualify for the service due to their annual income. Under the 2003 federal poverty guidelines, a single-member household with an annual income up to \$35,920 would qualify for the proposed service. The Maryland Department of Legislative Services notes in the record that it is unclear how the income will be verified.

Local jurisdictions would have to provide up to \$25,000 to receive a \$100,000 grant, if eligible. However, it is unclear how many local governments use volunteer drivers. The impact on smaller counties or municipalities was projected to be greater than on larger localities.

During the 2001 Maryland General Assembly session the MTA, introduced a similar bill to create a State Job Access Program. This bill passed both the Maryland Senate and House of Delegates, and was signed by Governor Glendenning on April 20, 2001. The legislation outlines the application procedures and matching funding requirements, and while it does not mandate a specific annual allotment for the Job Access Program, it ensures that Maryland's program will exist beyond the federal program. The State, though, anticipates that the Federal Job Access and Reverse Commute Program will be reauthorized and these funds can continue to support Maryland's efforts to connect low-income workers with employment opportunities.¹²³

Kentucky

The *Universal Design Handbook* prescribes the following design guidelines:

1. Finished hallways should be 42" wide.
1. All doorways, including closet doors and entry doors, should be 32" wide at minimum. Specifications for entry platforms also are included.
2. Ground level and elevator accessible units must have a minimum of one full universally designed bathroom.
3. Single lever or ADA-approved faucets must be installed at all sinks, showers, and tubs.
4. Electrical outlets have to be installed at a minimum height of 15" and light switches, fan switches and thermostats at a maximum height of 48".

All units must have a least one universally designed bedroom on the ground level or elevator accessible floor.

Washington

In 2005, Washington passed statute 43.31.460 entitled, SEED act—Individual development account program—Rules, updating the IDA law. The pertinent section is:

An individual development account program is hereby established within the department for the purpose of facilitating the creation by sponsoring organizations of individual development accounts for low-income individuals.

(1) The department shall select sponsoring organizations to establish and monitor individual development accounts using the following criteria:

(a) The ability of the sponsoring organization to implement and administer an individual development account program, including the ability to verify a low-income individual's eligibility, certify that matching deposits are used only for approved purposes, and exercise general fiscal accountability;

(b) The capacity of the sponsoring organization to provide or raise funds to match the contributions made by low-income individuals to their individual development accounts;

(c) The capacity of the sponsoring organization to provide or arrange for the provision of financial counseling and other related services to low-income individuals;

(d) The links the sponsoring organization has to other activities and programs related to the purpose of chapter 402, Laws of 2005; and

(e) Such other criteria as the department determines are consistent with the purpose of chapter 402, Laws of 2005 and ease of administration.

(2) An individual development account may be established by or on behalf of an eligible low-income individual to enable the individual to accumulate funds for the following purposes:

(a) The acquisition of postsecondary education or job training;

(b) The purchase of a primary residence, including any usual or reasonable settlement, financing, or other closing costs;

(c) The capitalization of a small business. Account moneys may be used for capital, land, plant, equipment, and inventory expenses or for working capital pursuant to a business plan. The business plan must have been developed with a business counselor, trainer, or financial institution approved by the sponsoring organization. The business plan shall include a description of the services or goods to be sold, a marketing strategy, and projected financial statements;

(d) The purchase of a computer, an automobile, or home improvements; or

(e) The purchase of assistive technologies that will allow a person with a disability to participate in work-related activities.

(3) An eligible low-income individual participating in the program must contribute to an individual development account. The contributions may be derived from earned income or other income, as provided by the department. Other income shall include child support payments, supplemental security income, and disability benefits.

(4) A sponsoring organization may authorize a low-income individual for whom an individual development account has been established to withdraw all or part of the individual's deposits for the following emergencies:

- (a) Necessary medical expenses;
- (b) To avoid eviction of the individual from the individual's residence;
- (c) Necessary living expenses following loss of employment; or
- (d) Such other circumstances as the sponsoring organization determines merit emergency withdrawal.

General Information Regarding Medicaid Buy-In

There is some support among consumers and advocates for broadened income and asset rules in the Medicaid Buy-In Program. The state is examining the feasibility of exempting Independence Accounts for all Medicaid eligibility categories.¹²⁴

As states face fiscal challenges, policymakers are seeking tools to enable them to reduce work disincentives in Medicaid with a minimal level of net costs.¹²⁵ When designing their Medicaid Buy-In programs, state policymakers are facing the challenge of simultaneously achieving their policy objectives and controlling costs.¹²⁶ In designing a Medicaid Buy-In Program, state policymakers must weigh the amount of subsidy they can provide against the amount they will require the individual to pay as a premium. To help offset program costs, some states are considering premiums modeled on private health insurance premiums, with a cap pegged to the maximum premium amount required of a state government employee.¹²⁷

A high premium may discourage some people from participating in the Medicaid Buy-In Program. Their willingness to expend their resources is likely to depend on the relative value they place on the extra benefits available to them in the Medicaid benefits package. An individual anticipating extensive use of personal care or prescription drug services may not be discouraged by high premiums. On the other hand, a person whose primary health care needs are met through Medicare may be unwilling to pay high monthly premiums for wrap-around coverage.¹²⁸

The Balanced Budget Act of 1997 and TWWIA authorized states to enact Medicaid Buy-In programs for workers without disabilities. These laws provided state policymakers and other stakeholders an opportunity to focus on issues associated with employment of People with significant disabilities. Every state starts from a different baseline as it relates to Medicaid eligibility rules, the relationship between SSI eligibility and Medicaid, SSI state supplementation, and the implementation of existing SSI work incentives. The purpose, function, and size of a state's Medicaid Buy-In Program vary depending on its policies governing eligibility for cash benefits, work incentives, and health coverage through Medicaid. The design of a Medicaid Buy-In Program must be viewed in the context of a state's overall Medicaid Program, other state-specific initiatives, and fiscal considerations.¹²⁹

Buy-In programs (enabling people with disabilities with increased earned income to continue Medicaid eligibility) have become a key component of state efforts. States are implementing Buy-In programs (and related programs and supports) not as welfare programs, but as programs that help states make productive use of all of their human capital resources. Many policymakers support Buy-In programs as a means to increase workers with disabilities' participation as productive citizens of states. That is, such programs are seen as a means to "enhance a state's economic status; not simply as a means to enhance access to health care."¹³⁰

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