STATE ADMINISTERED SPENDING FOR CONNECTICUT CITIZENS WITH DISABILITIES

Do THE DOLLARS PROMOTE COMMUNITY?

A Report to the Connecticut Council on Developmental Disabilities

by

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I. Introduction

This report was commissioned by the Connecticut Council on Developmental Disabilities. The Council is an organization of persons with disabilities and others who seek to share with members of the broader community the talents and experience of people who have a disability. In order to do this, they encourage people with disabilities to develop their particular talents, and at the same time they work to break down barriers that separate people who do not have a disability from those who do.

As part of their effort to understand how State-supported programs meant to help persons with disabilities affect the Council's work, Council members asked the Center for Economic Policy Analysis to review the overall structure of Connecticut's service system. Our task was to analyze aggregate spending patterns to determine whether or not they promote community relationships among persons with disabilities and persons without. In other words, we were not asked, and we did not try, to evaluate individual programs' achievements and shortcomings, nor did we calculate whether too much or too little money is being spent to satisfy any particular "need."

Rather, we examined total disability-related expenditures to find out whether they provide four conditions that are the minimum requirements for people with disabilities to be able to develop community relationships. These criteria reflect the amount and type of responsibility that persons with a disability are permitted to exercise and the opportunities that programs create for persons with and without a disability to interact with one another. The criteria and how we used them are fully explained in Section III.

Our analysis found that well over half of Connecticut's disability spending fails to provide even one of the minimum prerequisites for community. This is shown in the first column of Exhibit 1. A third of disability-related spending does offer one (but only one) of the prerequisites, while just six percent—less than $98 million out of more than $1.6 billion—provides all four community prerequisites.

Methodology

Our charge was to describe the impact of aggregate State spending for the entire system of programs meant to serve persons with disabilities in Connecticut. The investigation, therefore, extends to all expenditures that in some way pass through State government. Among these are programs directly supported by the State, federal grants that pass through the State government, some private donations received by the State, payments made by the State to towns and boroughs as reimbursement for State-mandated property tax relief for persons with a disability, and State taxes forgone as a result of disability-related tax credits or exemptions.

The investigation excludes a considerable number of other programs which do not receive State-administered funds, such as federal Supplemental Security Income and other programs administered directly by the federal government, local expenditures for paratransit, locally funded property tax relief even if mandated by the State, and any other locally funded disability services. It also excludes programs which may be administered by the State but which are not explicitly designed to aid persons with disabilities. For example, although many persons with disabilities receive food stamps, the program is excluded because eligibility is determined solely by Income rather than the presence or absence of a disability. As a result, our analysis does not include a significant amount of expenditures which may incidentally benefit persons with disabilities by virtue of their poverty status.
EXHIBIT 1

Most disability-related spending does not provide even one prerequisite for community.

$1,600,000,000

$1,400,000,000  --  $883,214,645

$1,200,000,000  --  $800,000,000

$1,000,000,000  $547,513,968

$600,000,000  --  $72,817,660  $97,679,211

$400,000,000  --  $14,338,130

$200,000,000  --

Total spending in all categories: $1,615,563,614
The analysis is based on State Fiscal Year 1992-93 program descriptions and expenditures, the most recent period for which reliable data were available.

A. Identifying Programs. We compiled an initial list of disability-related programs from the 1993-1995 Governor's Budget for the State of Connecticut. This list was reviewed with staff members of several State agencies who supplied us with extensive additional information. In the end, we had 177 programs with at least some funding administered by Connecticut State government which directly or indirectly benefits persons with disabilities. Appendix 2 is a complete list of these programs.

For each program, we collected descriptive information that included regulations, brochures, applications, and program guidelines. When printed matter was not available, we gathered information via informal interviews with agency administrators and program staff. In cases where agencies failed to provide adequate data, we relied on program descriptions in the Governor's Budget.

The information we eventually obtained for different programs varies greatly in its depth and detail. Some agencies provided complete program guidelines, including accounts of actual practices and operating procedures. Others provided only general activity summaries. In the most extreme case, we were told that a program existed but that no data were available that would permit even an estimate of its dollar cost. This lack of precise information may have resulted in the misallocation of some program expenditures. However, our judgment is that any such misallocations, if they exist, must on the whole be insignificant because the vast majority of our classifications are based on detailed program information.

B. Calculating Program Expenditures. The total cost of delivering any program includes not only direct program expenditures, such as for personnel and supplies, but also indirect costs for administration. Direct costs were obtained from estimated final spending for Fiscal 1992-93 in the Connecticut State Budget 1993-95: A Summary of Revenue, Appropriations and Bonds Authorized by the General Assembly (Connecticut General Assembly, Office of Fiscal Analysis, August 1993) or from special tallies provided by agency personnel. These were augmented by the addition of employee fringe benefits, as explained later in this subsection.

Indirect costs occur at two levels. The first is at the agency responsible for delivering the service. This was obtained by calculating direct costs for each program as a fraction of total agency expenditures for all items other than administration. We then multiplied total agency administration by this fraction to get the prorated share of agency administration allocable to the program.

The second level of indirect costs is central state administration. It includes the Governor's Office, Legislature, Office of Policy and Management, and other agencies with a general government function (excluding line items related to fringe benefits, which are explained in the next paragraph). We obtained this by calculating central administration as a fraction of total state expenditures for all items other than central administration. We then multiplied direct program costs plus agency-level administration by this fraction, which was about three percent, to get the amount of central administration allocable to each program.

For both direct and indirect costs, we had to make one further adjustment. Under budgeting practices used in Connecticut, employee fringe benefits are reported only as grand totals for all State workers combined, rather than being assigned to the program and agency where employees actually work and where the expenditures are incurred. Relying on information provided by State officials, we added fringe benefits amounting to 28.27 percent of the personal services lines in both direct and indirect costs.
EXHIBIT 2

More than 70% of spending is for medical, housing, and education services.

Total spending in all categories: $1,615,563,614. See Appendix 2 for details.
Finally, some programs target not only persons with a disability but also other specified groups within the population, such as the elderly or veterans. For these, we isolated the amount spent for persons with a disability on the basis of information provided by program administrators. Census or other data, and our own experience. Explanations of how we did this are in Appendix 1.

Our tally of the total cost allocable to disability-related spending is summarized in Exh. 2, backed up by a complete listing of all 177 programs in Appendix 2. Of $1,615,563,614 spent in Fiscal 1993, 34.5 percent paid for medical services, 20.2 percent for housing, and 17.6 percent for education. The remaining 28 percent was divided among support services, unrestricted cash payments, employment and training, counseling, case management, recreation, transportation, and miscellaneous other services that together account for less than 0.5 percent of the total.

**Prerequisites for Community**

People often do not think about the most commonplace features of their lives, things that they literally take for granted. For example, it is said that nomads who spend their entire lives in a desert rarely think about sand and can describe it only with difficulty. Similarly, people who have breathed only clean air, without ever experiencing air pollution, do not reflect on air quality and cannot fully appreciate the importance of clean air compared to its alternatives. In the same way, people without a disability rarely consider the most common aspects of the freedom they experience in the communities where they live.

This report attempts to bridge the gap in experience between persons with and without a disability by focusing on certain prerequisites for community that people without a disability take for granted. In order to isolate the most important prerequisites, we met with persons with disabilities and their representatives, service providers, agency administrators, and other interested parties. In addition, we reviewed literature in the field to get a sense of some of the standard concepts and debates, and we consulted with colleagues who have done similar work.

This led us to four related elements that are necessary prerequisites for community. These elements do not by themselves guarantee full community life for anyone who enjoys them, with or without a disability, but they are the minimum necessary for community to be possible. Furthermore, they must all be present simultaneously, much as a table cannot stand firmly unless all of its legs are present and functioning.

**A. Authority To Hire and Fire Service Providers.** Everyone periodically relies on a professional to provide certain services, and most people most of the time can choose who this professional will be. Therefore, our first prerequisite for community is whether persons with a disability have this same opportunity: From caregivers for the most intimate of hands-on services, such as assistance when going to the bathroom and bathing, to technically skilled therapists and the like, can persons with a disability hire and fire their own service-provider?

The answer to this question has far-reaching economic and social implications. For example, when persons with disabilities and their representatives are allowed to decide who will provide services they need, the service-user effectively offers a resource (employment) to another community member, and both parties come together out of their own preferences to form a mutually beneficial relationship. The service-user imposes clear incentive on the provider to improve the quality of service delivered in order to obtain or keep employment.
EXHIBITS

For every dollar spent on programs which allow users to hire and fire their service provider, $7.94 is spent on programs that do not.
The provider, on the other hand, gains new freedom to act independently and demand responsible behavior from the recipient, since providers who can be hired or fired can more easily define the conditions under which they will work for a user considered irresponsible and uncooperative. Moreover, when service-providers are hired directly by the people they are supposed to serve, they avoid the divided loyalties and tensions that inevitably arise from being hired and managed by program staff who are independent of users.

In addition, beyond the issues of control in the employer/employee relationship, the authority of consumers to hire and fire their own service providers allows both parties to enter into a relationship based on more than just the basic parameters of the service. For example, someone who enjoys keeping late hours and who needs a personal care assistant will want an assistant who is willing to work later at night and who, from the provider's perspective, prefers to sleep later in the morning. If the service-user is able to hire the worker, these complementary preferences can be satisfied in a mutual relationship that extends beyond the impersonal tasks of the job.

Conversely, consumers with authority to hire and fire providers must also assume responsibility for seeing that their needs are properly met. They must move beyond reactive complaining, demand-making, and passive acceptance in order to take action on their own behalf. Perhaps most importantly, consumers must be prepared to live with the consequences of their choices. In short, the authority to hire and fire service-providers requires the user to balance freedom of choice with responsibility for outcomes, just as all members of a community are required to do.

Nevertheless, for every dollar spent on programs allowing users authority over the hiring and firing of service-providers, $7.94 is spent on programs which do not allow them to choose providers. This is shown in Exh. 3.

B. Responsibility To Act Without an "Expert's" Approval or an Authorized Plan.
Everyone has encountered situations in which they must obtain someone else's approval before they can act. However, most people most of the time do not face such a constraint, and this is the second prerequisite for community: Can persons with a disability acquire the benefits of a program whose stated goal is to help them, without first obtaining prior professional approval of a plan?

The plans we are speaking of here include those required for participation in special education programs, in which a parent is one member of a committee dominated by service professionals who may or may not personally know the child (other than through test scores); plans required of people attempting to enter independent living and group home programs; spending plans required for certain cash assistance and "waiver" programs; and many others. In practice, these plans often seem to serve the function of rationing access to services and sometimes directing recipients to programs that might otherwise be underutilized; but the purpose of a required plan did not enter our evaluation. In order to focus on only the most limiting aspects of plans, we excluded from consideration the routine administrative review that prospective service-recipients must undergo to certify that they meet technical eligibility criteria, such as having a specified disability or income level.

When service-recipients can proceed without a plan, they and their circle of supporters prioritize for themselves what services and service levels they want. They therefore assume responsibility for living with the outcome of their own choices. This is much different from what happens when a requirement for prior expert approval first permits, and then encourages, passive acceptance or voracious consumption of whatever services the expert approves. Service recipients eventually lose control over events in their lives and can become apathetic or hostile, even if the expert's plan generally meets a recipient's narrowly defined disability-related needs.
EXHIBIT 4

For every dollar spent on programs that do not require a provider-approved plan, $10.08 is spent on programs that do.
EXHIBIT 5

For every dollar spent on cash assistance, $13.36 is spent on service and commodities.
Service-providers, too, are isolated from the consequences of decisions they make. They neither enjoy the benefits of a plan well made nor suffer the harm of a plan poorly made or executed. Overall, any system in which the link between choice and consequences is broken in this way has little possibility for self-correction because those in decision making positions lack incentives to adjust their course of action based on outcomes.

Programs which require expert authorization or a service plan sanctioned by staff or hired consultants account for more than ten of every eleven dollars spent to aid persons with disabilities, as shown in Exh. 4.

C Discretion To Allocate Program Resources. The normal state of affairs for most people is that they have a certain amount of cash income in any time period, and they must choose how to allocate it. They can buy whatever they find affordable, they can give some of their money to charities or other individuals more needy than themselves, and they can save for the future any money they do not spend now.

The most obvious benefits of cash over services are the discipline and responsibility that cash teaches. Holders of cash may feel they have unlimited discretion over how to spend it, but when the money is gone it’s gone. However, unrestricted cash also does much more than this. It fosters creativity, as people try to figure out new ways for obtaining what they want with the least expenditure, thus leaving more of their cash for other purposes. It establishes the possibility of community relationships in which people pool their resources to begin a business or purchase something no one of them could afford alone. Conversely, it builds incentives for the vendors of goods and services to develop new and better ways for meeting the needs of persons with a disability, since cash empowers buyers to reward better vendors with higher prices.

In these and many other ways that most people take for granted, the discretion that normally comes from cash income facilitates the growth of personal responsibility. Therefore, the third prerequisite for community is whether-program benefits are provided as cash rather than as commodities, direct services, advocacy, case management and the like. In order to preserve the distinction among the four prerequisites, all cash assistance is counted here, even though some of it is not unrestricted and does not provide the full measure of discretion described above. For example, some programs provide cash, but recipients are able to access the money only after getting approval of a plan for how they will spend it. Such programs are included among the $112.5 million worth of cash assistance programs portrayed in Exh. 5, but they were classified as needing a pre-approved plan in Exh. 4. The amount of unrestricted cash payments, as illustrated in Exh. 2, is $95.7 million. This is an example of how the community prerequisites are interdependent and why all four must be considered together.

This particular prerequisite addresses head-on some of the assumptions that people who are not disabled make about the capacity or lack of capacity to live their own lives that persons with a disability and their support network have. One program, for example, provides people who are disabled with specially modified vehicles. The person who is ultimately to receive the vehicle first must go through an assessment process to determine that, in fact, they need it. Then, they must see an expert about what kind of vehicle and modifications are appropriate. Next, specifications are written by program staff and put out to vendors for bidding. Sometime later, the person with the special transit need goes to pick up the vehicle. During this whole process, they never see a dollar, never have to comparison shop or weigh features and costs against one another, and never articulate or prioritize their needs to anyone accountable directly to them. On the other hand, someone who has enough money of their own, with or without a disability, finds that their judgment is assumed to be adequate.

Only a small portion of expenditures, less than one of every fourteen dollars spent, supports programs providing cash assistance.
EXHIBIT 6

For every dollar spent on programs supporting integrated environments, $1.24 is spent to support segregated environments.

$1,600,000,000

$1,400,000,000

$1,200,000,000

$1,000,000,000

$899,133,298

$690,301,315

$600,000,000

$56,129,001

$400,000,000

$200,000,000

Integrated Environment

Segregated Environment

Unallocable
D. Integrated Program Settings. The first three community prerequisites measure the individual responsibility accorded to and assumed by persons with a disability. Now we consider the setting in which programs are delivered: Does this setting allow people with disabilities an opportunity for more than incidental interactions with non-disabled people other than program staff?

Such interactions, although hardly sufficient in themselves for community, are a minimum condition for the possibility of personal relationships that cross the traditional barriers between persons with and without a disability. Because virtually all programs claim as one of their goals the maximum feasible inclusion of people with disabilities in non-disabled settings, we focused on the program setting itself. As the program is being delivered, does it incorporate interactions that bring people with and without disabilities into contact with one another?

Programs that do not provide integration are costly in many ways. They deny "mainstream" society the contributions persons with disabilities could make. They burden taxpayers and their representatives with the never-ending task of constantly deciding for others, while keeping these others dependent and childlike. And they deny persons with disabilities the opportunity to form alliances and relationships with people who are neither disabled nor trained service professionals but who might better complement their needs and abilities.

Still, less than half of State-administered disability spending supports integrated settings, as Exh. 6 shows. Four of the five largest programs in integrated settings are administered by what was the Department of Income Maintenance in Fiscal 1993, now part of the Department of Social Services. These are the State Waiver for the Mentally Retarded Medical Care and Medicaid programs; the State Supplement for Aid to the Aged, Blind, and Disabled; and Medicaid Home Health Services (excluding Aid to the Blind and Aid to the Disabled). The only other program accounting for more than five percent of the expenditures in integrated settings is a prorated portion (see Appendix 1) of the Department of Education's Regular Special Education Reimbursements to Towns. Together, these programs account for just under 60 percent of all expenditures in integrated settings.

The difference in total spending between programs operating in integrated and segregated settings is significantly less than the differences in spending for hiring and firing, responsibility to act without an approved plan, and discretion over the allocation of program resources. This may be, in part, because the concept of inclusivity has been widely discussed and accepted for a number of years, so that it has begun to make its way into program regulations and descriptions as a goal and objective.

IV. Accountability

If consumers and their representatives are given responsibility for choosing and managing the services they receive, should they also be held accountable for the results of their actions? Yes, of course.

However, most public programs that affect people with a disability seem to begin from a different assumption. This assumption is that people, specifically, persons with a disability, if left to themselves at best don't know how to take care of themselves and at worst will actually harm themselves. Therefore, the role of government becomes not simply to provide services but also to create and enforce controls that will prevent people from harming themselves. One consequence is the conviction that public programs should be structured in such a way that that people cannot avoid being taken care of and cannot harm themselves. Given the initial assumption, this is a perfectly logical conclusion.
On the other hand, there is always the possibility of error whenever human beings make a choice. The appropriate question, therefore, is who has the opportunity to be wrong. As long as government officials and professional service providers are willing to accept this opportunity, then people with a disability who are afraid of making a mistake should be able to choose an assistant, such as a social worker, who will order their lives and make all decisions for them. Persons with a disability who take this option will then be bound as a consequence of their decision to live with any errors made by the assistant.

Other people with disabilities who are not afraid in this way should be able to choose for themselves, with the understanding that they will be responsible for their own errors. If, for example, their benefits are converted to a periodic cash allowance and they spend the money on a wheel chair that does not work or a van that does not properly meet their needs, they will not receive additional compensation to correct the error. As a consequence of their decisions they will have to live with any errors they make, but they will also enjoy the benefits of any wise choices they make.

Clearly, one can envision situations in which errors are made that are life-threatening, such as spending so much money as soon as it is received that not enough is left to pay for food or rent for the rest of the period. One reality is that errors with significant consequences such as this are made by professionals in the system now. Another is that, whatever we think of personal responsibility, most taxpayers would probably consider it unconscionable to withhold further aid in such cases. The minimum possible aid can be provided, with a clear understanding that further mistakes of this type will result in the loss of decision-making power for the recipient.

The point is to examine the underlying assumptions on which public programs rest in order to determine where the burden of proof should lie. If one begins from the assumption that people do not know how to care for themselves and that life-threatening errors will be the norm rather than the exception, then programs will be structured so as to control all spending centrally and eliminate the possibility both of client mistakes and client extraordinary achievement—at the cost of possible mistakes made by service providers. If one begins from the assumption that people, being closer to their own lives and concerns, will usually choose what is right for themselves—assuming that they have appropriate alternatives—then programs will be structured so as to provide maximum responsibility for clients until and unless they clearly prove they cannot handle it.

IV. Summary

We have identified four characteristics that must be present in a social service system if it is to respect the individuality of the people it was created to benefit and afford them opportunities for meaningful community relationships. Program service expenditures, taken as a whole, should reflect a broad presence of these characteristics throughout the system. If any one of the characteristics is missing, the possibility for community is compromised in the same way a table is compromised by the absence of a supporting leg.

Exh. 7 summarizes our examination of more than $1.6 billion that is spent in 177 programs for Connecticut residents with a disability. Of this total, slightly more than eleven percent permits recipients or their support community to hire and fire their own service providers. Less than nine percent assumes recipients have a clear enough understanding of their own needs that they can access services without first obtaining an expert's prior approval for a plan. Less than seven percent gives recipients discretion to choose services and service providers by paying benefits in the form of cash. And 43 percent, still less than half, is delivered in settings where people with and without a disability might come into contact with one another.
EXHIBIT 7

Only a small percent of disability spending supports the prerequisites for community.
A system such as this that fails to support community deprives its intended beneficiaries of control over their own lives and of the opportunity to become responsible consumers. The resulting inefficiency adds to the cost of providing assistance in that some of the services are inappropriate and overshoot needs, but they are utilized by consumer because they possess at least some element of a much less expensive service that is more highly desired but is not available. We have heard, for example, of people in very costly visiting nurse or other home-medical programs who do not need the medical care but who seek out the service for the occasional companionship it provides. This must be frustrating not only for the service-user but also for the visiting nurse.

More generally, a system that lacks the prerequisites of community for service-recipients also denies to service-providers the opportunities to be creative and resourceful in providing their services and to develop more satisfying relationships with clients. Program regulations and service-providers become constrained by the consequences of assuming that people with disabilities and their circle of supporters either won't or don't know how to take care of themselves. If more responsibility were given to clients, not only would clients be freed from the burden of having their lives managed by someone else, but also social workers would be freed from the impossible burden of trying to manage other human beings' lives. This would enable social workers to do the more fulfilling work of helping people with disabilities realize their potential and make the unique and often surprising contributions to society that only they can make.

V. Recommendations

A. The primary and explicit starting point in all discussions about programs and policy for people with disabilities should be the extent to which expenditures promote or do not promote the prerequisites for community. Discussion should neither begin from nor be sidetracked into the question of whether a particular community-building program is less or more expensive than some other program that does not support community.

In other words, the central issue is how people with and without disabilities want to relate to one another. Program cost is important, but in its proper place. Few people, for example, ever buy the lowest cost version of any good or service for themselves. They review competing products' characteristics and pay more than rock bottom in order to get not only the particular characteristics they want but also higher quality.

In a similar fashion, taxpayers and the leaders of taxpayer organizations have repeatedly demonstrated that they are willing to pay reasonable amounts for programs whose goals they understand and value. This is where DD Council energies should be concentrated. After sufficient agreement has been reached on the importance of programs that provide the prerequisites for community and after specific programs have been developed that do this, then and only then is it appropriate to debate the relative costs of different programs and program structures. Cost, in other words, becomes relevant only when similar programs—namely those that support community—are being compared against one another, not when they are being compared to dissimilar programs that do not support community.

In the final analysis, a program that does not achieve what its sponsors want really has little or no value, whatever its cost, whereas a program that does achieve widely supported goals may be worth a great deal, to program beneficiaries and taxpayers alike.

B. The DD Council should sponsor local hearings throughout the state to gather testimony about the ways that current regulations and guidelines prevent people with disabilities from developing community relationships. The purpose should be to develop specific program changes that will create the prerequisites of community. Witnesses should be asked to comment on the following questions and statements of position:
1. **How can benefits be provided in the form of cash rather than services?** For example, calculate the amount now spent to provide the full array of services received by each person, and simply offer an equivalent amount to monthly or quarterly dollar payments, indexed for future inflation.

The recipient of cash may choose to purchase many of the same services now received, sometimes even from the same providers. However, the entire dynamic of the relationship will be different because persons who need services will now be able to work out individualized agreements with the providers who best meet their specific desires.

2. **How can the requirement for pre-approved service plans best be eliminated?** One possibility is that case workers who now develop these plans can become bona fide consultants whom clients are free to seek out for their special knowledge of the system. Persons with a disability should also be able to seek another advisor of their choice or no one, without jeopardizing access to benefits.

   This is, for example, the way Social Security benefits are provided: No one must spell out in advance how they will spend the money as a condition for receiving it.

3. **How can service-recipients gain the ability to hire and fire those who provide their services?** Such power is implicit to the substitution of cash for services. As an interim step if this substitution is not implemented, service-recipients can be given vouchers redeemable for the services that State policy makers have decided they should have. Recipients would redeem these vouchers with providers of their choice, who in turn would receive funding in proportion to the vouchers they could attract.

   While not offering as much responsibility either to service-providers or to persons with disabilities as cash would, a voucher system still has clear advantages over the present system. People with disabilities will benefit by being able to select providers who meet their needs better than current providers. Service providers, rather than writing proposals to the State or approaching the legislature directly for funding, would be accountable to those for whom they presumably exist: service-recipients. Private agency providers would be freed from the need to compete in the politically charged arena of writing funding proposals to meet changing State guidelines. Instead, they would be funded automatically, subject only to the condition that their services are good enough to attract customers with vouchers.

4. **How can more integrated program settings be achieved?** A related issue is how to encourage and nurture circles of support that consist of concerned friends and family members of someone with a disability. These (non-professional) friends and family members can satisfy many of the basic needs of the person at the circle's center. If they require specialized assistance, they can call on an appropriate professional of their choosing, much as anyone else periodically calls on a professional. Mechanisms for creating and maintaining such circles should be explored.
C Review State (and federal, where necessary) regulations regarding the certification and oversight of service providers. This review should have two foci:

1. Regulations should be eliminated that impose unnecessary or irrelevant conditions and restrictions on who can provide services and how those services can be provided. In the jargon of economics, this means that barriers to the entry of new service-providers should be reduced to the bare minimum needed for genuine protection of service-recipients. If barriers are not reduced, then cash or vouchers provided to people with disabilities will have much less meaning than they should because people's range of choices will be limited. High entry barriers also inevitably increase the cost of any product or service, so the lowering of entry barriers is desirable even on purely economic grounds.

2. As greater responsibility is transferred to the providers and users of services, attention should be paid to the possible need for new regulations to prevent systematic abuses that might creep into the system.

D. Develop ways for people with a disability to earn the money that is now appropriated for them simply because they have a disability, and not because they do anything productive. The opportunity to earn one's own means of support is central to most people's sense of well-being, but this fact has rarely been considered in the design of disability-related programs. One reason is the assumption, discussed in Section IV, that persons with a disability are so limited that they either can't or won't take care of themselves.

Because this issue has been so neglected, the DD Council can fill a void by taking the lead in fashioning programs that recognize the talents of people with a disability and create opportunities for them to earn their benefits. At the very least, people who are already working at low-paying jobs can have their benefits converted to a wage supplement high enough for them to hire their own job coach, provide transportation, and meet the other demands of their particular situation. People who are not working and their support communities need opportunities to discover what their talents are and to experiment with how these talents can best be used. This can fruitfully become a major focus of the DD Council's activities in the coming year.
APPENDIX 1

TECHNICAL NOTES ABOUT ALLOCATING PROGRAM EXPENDITURES

A Prorating Expenditures for Persons with Disabilities When a Program Also Serves People Without a Disability

Several programs have eligibility criteria that include people with and without disabilities. Whenever we became aware of such a situation, we sought additional information in order to isolate only that portion of total spending that could be attributed to persons with a disability. How we did this for each program is explained below.

Department of Children and Families

Extended Day Treatment: We took 80 percent of total expenditures, based on administrative staff estimates that 80 percent of users have a disability.

Unified School District # 2: We took 75 percent of total expenditures based on staff estimates that 75 percent of users have a disability.

Department of Corrections

Educationally Deprived Children: No data about program enrollees were available. We took half of total expenditures after administrative staff confirmed our estimate that 50 percent of users have a disability.

Department of Education

Compensatory Education: We took seven percent of total spending, based on enrollment data showing that this percent of students is classified as Special Education.

Vocational-Technical Schools: Agency staff provided the amount of spending for the special education students in this program (1,700 out of 9,598).

Vocational Training and Job Preparation: Seventeen percent of Connecticut's population have a disability. We rounded this down to 15 percent on the reasoning that not all disabled children and youth attend school.

Board of Education and Services for the Blind

Workshops, Production Program: We took 80 percent of total expenditures, based on administrative staff estimates that 80 percent of users have a disability.

Sheltered Workshops: We took 80 percent of total expenditures, based on administrative staff estimates that 80 percent of users have a disability.

Department of Labor

Job Training Partnership Act, Section IIA: We took 13 percent of total program spending, based on data in the 1993 JTPA Annual Report showing that 17 percent of participants have a disability.
Job Training Partnership Act. Section IIB: We took 16 percent of total program spending, based on data in the 1993 JTPA Annual Report showing that 17 percent of participants have a disability.

Protection of Employees. Regulation of Working Conditions for the Handicapped: We took one percent of total expenditures, based on administrative staff estimates that one percent of their time is spent handling cases pertaining to persons with disabilities.

Select Ability Matching Program: No expenditure information was provided by staff. As a result S A M expenditures are not included in the analysis, but the program is listed in Appendix 1 for the sake of completeness in our report.

Office of Policy and Management

State-Reimbursed Property Tax Exemption for Low-Income Disabled or Elderly Principal Residence: We assumed that the incidence of disability among the elderly population is about twice the state’s overall rate of 17 percent. However, since persons of any age with a disability may be less likely to own their own homes, we rounded down to 30 percent for an estimate of the total program benefits going to persons with a disability.

State-Reimbursed Property Tax Exemption for Low-Income Disabled or Elderly Renters: We assumed that the incidence of disability among the elderly population is about twice the state’s overall rate of 17 percent. Since persons with a disability may be somewhat more likely to qualify for this program than the one restricted to homeowners, we rounded up to 40 percent for an estimate of total program benefits going to persons with a disability.

State-Reimbursed Additional Property Tax Exemption for Veterans Other Than with Total Disability: According to data provided by the U.S. Dept. of Veterans Affairs, for every veteran in Connecticut classified as totally disabled, 15.54 are classified as 10-90 percent disabled. Since we had the number of totally disabled veterans receiving benefits in various categories (married, unmarried, above and below certain income limits, living in towns or boroughs) in the exemption program for the totally disabled, we multiplied these numbers by 15.54 to estimate the number of partially disabled veterans. We then multiplied this calculated number of program participants by the average per capita benefit to get an estimate of total program benefits going to veterans with a partial disability.

Department of Revenue Services

Sales Tax Exemption for Oxygen and Blood Plasma for Medical Use, Prostheses, and Vital Life Support Equipment: We assumed that 80 percent of the expenditures qualifying for this exemption were made by persons with a disability or on behalf of such persons.

Department of Social Services

Neighborhood Assistance Program Tax Credits: This program provides corporate income tax credits for a portion of corporate contributions to qualifying non-profit organizations. One of 12 (.08333, rounded to 8 percent) eligible types of recipient is organizations providing certain disability-related services. We assumed that eight percent of program benefits go to such organizations. Note that the direct expenditures for this program are the amount of forgone State tax revenue, not the amount of corporate contributions on which applicants base their claim for the credit. This is consistent with our project focus on spending that passes through the State.
Medicaid-Durable Medical Equipment Net of Spending in the Aid to the Disabled and Aid to the Blind Programs: We took 90 percent of total spending, on the assumption that at least this proportion of users has a disability.

B. Allocating Expenditures When Part of a Program Provides a Community Prerequisite and Part Does Not

Several programs provide some of their assistance in a form that provides a prerequisite for community but another part of their assistance in a form which lacks that same prerequisite. What we did in these cases is explained below.

Department of Education

Regular Special Education Reimbursement Grants: No direct information was available as to the environment associated with these special education expenditures. In order to ascertain it, we conducted a survey of the ten largest regular special education programs in the state, asking staff to estimate the percent of expenditures which supported "regular" classroom settings for students with disabilities as distinguished from "specialized" settings. Staff consistently estimated that 60 percent of expenditures supported regular settings, while 40 percent supported specialized settings. We therefore split expenditures in this program 60:40 between integrated and segregated settings.

Board of Education and Services for the Blind

Special Training for the Deaf and Blind: This program operates in both integrated and segregated settings. However, most program users reside in Institutional settings and most program services are provided in that context. We estimated this proportion to be 80 percent of total program expenditures. The other 20 percent is spent in integrated settings, such as supported apartments.

Special Book Purchases: This program supplies books and educational materials to visually handicapped children who receive their education in a variety of settings. Because 80 percent of students are in integrated environments, we assumed that 80 percent of the special book purchases occurred in integrated settings. The remaining 20 percent of children served by BESB are in segregated settings, so we counted 20 percent of program expenditures as supporting segregated settings.

Supplementary Services: This program supports students in public school special education activities. In the absence of any data specific to this particular program, we assumed that its expenditures were split between integrated and segregated settings in the same 60:40 ratio as the Dept. of Education's regular special education reimbursement grants (described above).

Department of Labor

Job Training Partnership Act, Sections IIA and IIB: Dept. of Labor staff estimated that the "vast majority" of JTPA programs operate in integrated settings. Only a few programs were known to occur in segregated settings. Based on this information, we allocated 90 percent of expenditures to integrated environments and 10 percent to segregated.
**Department of Mental Retardation**

CTH-Pilot Program: This program provides assistance in two different ways. Six of the eleven users were supported in family care home placements, and they accounted for 82 percent of program funds. We coded this as direct services. The remaining five users were assisted via direct cash grants to their families, with whom they live; and 18 percent of program expenditures were used for this purpose. We coded this part as income.

The 82 percent of expenditures that provided direct services was coded as not permitting the recipient to hire and fire their service provider, whereas the 18 percent paid as cash was assumed to provide this prerequisite of community.

Case Management: Case management cuts across all other DMR programs in ways that are not always clear. It is reasonable to assume, however, that it supports integrated settings to the same extent as other DMR programs. Therefore, we allocated expenditures in this program in proportion to all other DMR programs: 16 percent to integrated settings, 83 percent to segregated, and one percent unallocable.

**Department of Social Services**

Essential Services: This program provides assistance in two different forms. Users can receive income with which to pay for essential services or they can receive direct services. Program staff estimated that the split was about half-and-half. Based on this, we allocated 50 percent of the expenditures in this program to income and 50 percent to direct services.

The expenditures counted as income were assumed to offer recipients the authority to hire and fire their own service-providers, while the expenditures for direct services were assumed not to provide this authority.

Temporary Child Care-Crisis Nurseries. Activities under this program occur in both integrated and segregated settings. However, the majority of activities occur in segregated environments. Based on this, we estimated that 80 percent of program expenditures support in segregated environments, while 20 percent support integrated settings.

**C Program Expenditures Obtained from Other Than Published State Documents**

For a handful of programs, expenditures either were not reported or were incompletely reported in published State documents. These were:

**Department of Education**

Special Education-Transportation: We obtained data directly from agency administrative staff.

Regular Special Education Reimbursement: We calculated the amount of the reimbursement attributable educational purposes other than transportation by subtracting the amount for transportation (see above).
**Board of Education and Services for the Blind**

Special Education of Visually Handicapped Children: Program expenditures were prorated from staff estimates of the number of children served under each particular subprogram as a portion of the total number of children served. Our subsequent calculations were confirmed by administrative staff.

**Department of Labor**

Select Ability Matching: Although staff claim that such a program exists and is operational, they were unable to provide us with any expenditure Information. Because of this, we are unable to offer even an estimate of disability-related costs associated with the program. SAM expenditures are not included in the analysis, but the program is listed in Appendix 2 for the sake of completeness.

Job Training Partnership Act. Sections HA and IIB: Expenditures were obtained from the published JTPA 1993 Annual Report.
Appendix 2

STATE-ADMINISTERED PROGRAMS FOR PERSONS WITH A DISABILITY, FISCAL YEAR 1993

This appendix lists expenditures for disability-related programs administered by the State of Connecticut, organized by type of service and then by administering agency. Some agencies appear under more than one service-type heading. Because of the recent State Government reorganization, many programs are currently administered by a different agency than had them in 1993. Such programs are listed under the new agency name, with the former agency in parentheses.

The reported expenditures for a very small number of programs are negative. Agency staff confirmed that these are correct and that they generally represent adjustments from prior years for programs that may no longer exist. For information about how we obtained expenditure amounts, see Section II of the text and Appendix 1.

<table>
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<tr>
<th>Fiscal Year 1993 Expenditures</th>
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<tr>
<td><strong>ALL PROGRAM CATEGORIES, TOTAL</strong></td>
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<td><strong>Services and Commodities, Total</strong></td>
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<tr>
<td><strong>Medical, Total</strong></td>
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<td>Children &amp; Families</td>
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<td>State Receiving Home</td>
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<td>Education &amp; Services for the Blind</td>
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<td>Adult Svcs.-Independent Living Centers</td>
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<td>Adult Svcs.-Supplementary Relief &amp; Svcs.</td>
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<td>Mental Health</td>
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<td>Svcs. for the Deaf &amp; Hearing Impaired</td>
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<td>Mental Retardation</td>
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<td>Emplmt. Opps. &amp; Day Svcs.-Adult Day Treatment</td>
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<td>Campus Units-Clinical Svcs.</td>
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<td>Public Health &amp; Addiction Services</td>
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<td>Children with Sp. Health Care Needs-Birth to 3</td>
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<tr>
<td>Hosp. &amp; Med. Care-Home Health and C A M Agency Licensing</td>
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<td>Hosp. &amp; Med. Care-ICF for MR</td>
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<tr>
<td>Revenue Services</td>
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<tr>
<td>Sales Tax Exemp.-Oxygen, Blood Plasma, Prostheses, Etc.</td>
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<td>Social Services (DIM)</td>
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<tr>
<td>Medicaid-Comm. Waiver Services Net of AB &amp; AD</td>
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<td>Medicaid-Home Health Services Net of AB &amp; AD</td>
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<td>Medicaid-ICF for MR Net of AB &amp; AD</td>
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<tr>
<td>Medicaid-State Nursing Home (ICF/MR) Net of AB &amp; AD</td>
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<tr>
<td>Medicaid-State Waiver for MR Net of AB &amp; AD</td>
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<tr>
<td>Medicaid - Durable Medical Eq. Net of AB &amp; AD</td>
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<tr>
<td>Medical Assistance - CT Home Care Program</td>
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<tr>
<td>Med. Care for the Blind - Clinic &amp; Lab Svcs.</td>
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<td>Med. Care for the Blind - Durable Med. Eq.</td>
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<td>Med. Care for the Blind - Home Health Svcs.</td>
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<td>Med. Care for the Blind - Hosp. Inpatient</td>
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<td>Med. Care for the Blind - Hosp. Outpatient</td>
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<td>Med. Care for the Blind - ICFS</td>
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<td>Med. Care for the Blind - Medicare Buy-in</td>
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<td>Med. Care for the Blind - Pharmacy Svcs.</td>
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<td>Med. Care for the Blind - Physicians &amp; Other Practitioners</td>
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<td>Med. Care for the Blind - State Mental Hosp.</td>
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<td>Med. Care for the Blind - Town Assistance</td>
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<td>Med. Care for the Blind - Transportation</td>
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<td>Med. Care for the Blind - Vision Svcs.</td>
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<td>Med. Care for the Disabled - Chronic Disease Hosp.</td>
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<td>Med. Care for the Disabled - Clinic and Lab Svcs.</td>
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<tr>
<td>Med. Care for the Disabled - Durable Med. Eq.</td>
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<td>Med. Care for the Disabled - Durable Home Health Svcs.</td>
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<td>Med. Care for the Disabled - Hosp. Inpatient</td>
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<td>Med. Care for the Disabled - ICF for MR</td>
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<td>Med. Care for the Disabled - ICF</td>
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<td>Med. Care for the Disabled - Medicare Buy-in</td>
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<td>Med. Care for the Disabled - Pharmacy Svcs.</td>
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<tr>
<td>Med. Care for the Disabled - Physicians and Other Practitioners</td>
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<tr>
<td>Med. Care for the Disabled - Skilled Nursing Facilities</td>
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<td>Med. Care for the Disabled - State Mental Hosp.</td>
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<td>Med. Care for the Disabled - Town Assistance</td>
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<td>Med. Care for the Disabled - Transportation</td>
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<tr>
<td>Med. Care for the Disabled - Vision Svcs.</td>
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<tr>
<td>Elderly Svcs. - Promotion of Independent Living</td>
</tr>
</tbody>
</table>

**Housing, Total** $325,829,885

**Children & Families**
- Permanent Foster Care 879,880

**Mental Retardation**
- CLA - Comm. Residence 185,680,672
- Campus Units 126,105,219
- CTH - Famu/Ty Care Homes 4,906,148
- Other Private Residential Facilities 3,002,014
- CIA - Rent Subsidy 2,220,351
- CLA - Emergency Plants 597,505
- CLA - New Haven Regional Center 360,354
- CLA - Mansfield Relocation 190,760
- CTH - Pilot Programs for Client Svcs. 147,874
Social Sendees (DHR)
TBI-Grants 587,798
TBI Group Home-Transitional Living Grants 235,896
PRIDE 393,160

Education, Total $284,367,139

Children & Families
USD # 2 502,710

Corrections
Educationally Deprived Children 156,482
Handicapped State Grants 282,320

Education & Services for the Blind
Orientation and Mobility 474,008

Education
American Sch. for the Deaf 5,732,435
Compensatory Ed.-Ch. 1 4,686,273
Early Childhood Ed.-Ages 3 to 5 4,526,988
Sp. Ed.-Handicapped State Grants 23,852,186
Sp. Ed.-Excess Cost Reimbursements to Towns 9,149,902
Sp. Ed.-Regular Special Ed. Reimbursements to Towns 192,428,818
Sp. Ed.-Handicapped Children State Sch. Ch. 1 Set-aside 3,049,358
Voc. Training & Job Preparation 1,975,368
Voc. & Technical Schs. 4,116,855

Mental Retardation
Emphnt. Opps. & Day Svcs.-Early Intervention, USD # 3 10,059,983

Social Services (DHR)
Rehab Svcs.-Voc. Rehab, prchsd. Svcs., College 2,237,120
Rehab Svcs.-Voc. Rehab, Prchsd. Svcs., Other Post-secondary 1,586,591

Support Services, Total $170,531,259

Education & Services for the Blind
Adult Svcs.-Sp. Training for the Deaf and Blind 673,196

Education
Early Childhood Ed.-Young Parents, Birth to 3 10,627,639

Housing
Congregate Facilities Operating Costs 2,330,610

Mental Health
Corporation for Supportive Housing 1,209,063
### Mental Retardation
- Residential Svcs.-CLA, Family Reunion: 265,418
- Residential Svcs.-CTH Pilot Programs for Client Svcs.: 32,901
- Residential Svcs.-CTH Respite Care: 182,642
- Residential Svcs.-Supportive & Cooperative Living: 10,828,299
- Resource Svcs.-Comm. Respite Care: 234,822
- Resource Svcs.-Respite Care: 2,661,987

### Social Services (DHR)
- Rehab Svcs.-Independent Living Centers: 1,937,442
- Rehab Svcs.-Independent Living Svcs.: 383,568
- Family Spt. Program Grant: 179,785
- Personal Care Assistance-Handicapped: 518,545
- Personal Svcs. Program-Pilot: 544,690
- Svcs. to Persons with a Disability-Essential Svcs.: 14,852,038
- Svcs. to Persons with a Disability-Other: 242,448

### Social Services (DIM)
- Med. Care for the Disabled-State Waiver for MR: 122,826,168

### Employment and Training, Total: $79,254,257

#### Deaf & Hearing Impaired
- Job Development & Plant: 134,314

#### Education & Services for the Blind
- Adult Svcs.-Rehab Svcs., Basic Spt.: 288,682
- Small Business Enterprise: 638,397
- Voc. Rehab: 2,583,871
- Workshops-Home Industries: 1,122,189
- Workshops-Production Program: 334,859
- Workshops-Sheltered Workshop: 370,540
- Workshops-Work Activities Center: 807,257

#### Labor
- Committee for People with a Disability: 6,693
- JTPA-Title IIA (Year-round): 1,781,944
- JTPA-Title IIB (Summer): 1,647,647
- Reg. of Working Conds.-Handicapped. Elderly, & Children: 2,835

#### Mental Retardation
- Emplmt. Opps. & Day Svcs.-Sheltered Emplmt.: 31,366,154

#### Social Services (DHR)
- Adult Svcs.-Neighborhood Assistance Program Tax Credits: 80,510
- Rehab Svcs.-Assistive Technology Grants: 346,311
- Rehab Svcs.-TBI: 192,085
- Rehab Svcs.-Voc. Rehab Staff Training: 61,364
- Rehab Svcs.-Voc. Rehab. CRP. Job Seeking: 118,611
- Rehab Svcs.-Voc. Rehab. CRP. Other: 488,974
- Rehab Svcs.-Voc. Rehab. CRP. Site Asmt.: 1,733,172
- Rehab Svcs.-Voc. Rehab, CRP. Sptd. Emplmt.: 1,102,097
- Rehab Svcs.-Voc. Rehab., CRP. Time-limited Training: 1,721,774
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<th>Service Description</th>
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<td>Rehab Svcs.-Voc. Rehab. CRP, Voc. Training</td>
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<td>Rehab Svcs.-Voc. Rehab. Prchsd. Svcs.. Other Svcs.</td>
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<td>Rehab Svcs.-Voc. Rehab. Prchsd. Svcs.. Plant. &amp; Adaptive Eq.</td>
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<td>CONNARF-Brokering Costs</td>
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<td>CONNARF-Contract Amounts</td>
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<td><strong>Case Management, Total</strong></td>
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<td>Mental Retardation</td>
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<td>Resource Svcs.-Case Mgmt.</td>
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<td>Resource Svcs.-Family Spt., Family Plants.</td>
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<td>Rehab Svcs.-Transition</td>
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<td>Mental Retardation</td>
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<td>Emplmt. Opps. &amp; Day Svcs. -Comm. Experience Program</td>
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<td>Persons with Disabilities-Temp. Child Care, Crisis Nurseries</td>
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<td>Sp. Ed.-Transportation Costs</td>
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<td>Social Services (DHR)</td>
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<td>Public Transit-ADA Planning</td>
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<td>Public Transit-Sec. 16 Operating &amp; Administrative Costs</td>
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<td><strong>Advocacy, Total</strong></td>
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<td>Education</td>
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<tr>
<td>Mental Retardation</td>
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<tr>
<td>Statewide Mgmt.-Developmental Disabilities Spt. &amp; Advocacy</td>
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Protection & Advocacy for Persons with Disabilities
Abuse Investigations 795,103
Advocacy Svcs.-Advocacy Projects 428,886
Advocacy Svcs.-Client Assistance Program 120,438
Advocacy Svcs.-Comm. Transitions Project 394,157
Comm. Development & Support 559,698
Legislative Liaisons 60,006

**Counseling, Total** $2,419,395
Children & Families
Extended Day Treatment 2,142,296
Deaf & Hearing Impaired
Counseling Svcs. 277,100

**Communication, Total** $1,917,085
Deaf & Hearing Impaired
Interpreting Svcs. 461,878
Telecommunications Device for the Deaf System 1,410,649
Education & Services for the Blind
Mgmt. Svcs.-CT Radio Svc. 44,558

**Unallocable, Total** $1,788,186
Mental Retardation
Resource Svcs. -Staff Development and Training 1,788,186
Labor
Select Ability Matching Network: Department of Labor staff No information provided no information other than to confirm that this program exists.

**Legal, Total** $337,804
Protection & Advocacy for Persons with Disabilities
Legal Svcs. 337,804

**Unrestricted Cash, Total** $95,665,525
Mental Retardation
Policy & Management
Prop. Tax Circuit Breaker-Disabled or Elderly Renters 4,788,401
State-Reimb. Prop. Tax Exemp.-All Totally Disabled 448,764
State-Reimb. Prop. Tax Exemp.-Disabled or Elderly Residence 4,936,264
Social Services (DHR)
Voc. Rehab-Prchsd. Svcs., Maintenance & Transportation 1,087,684
Social Services (DIM)
State Supplement, AABD-AB 645,308
State Supplement, AABD-AD 79,569,282
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<th>Abbreviation</th>
<th>Full Form</th>
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