

NATIONAL
HOME OF YOUR OWN
ALLIANCE

*SUPPORTING CONNECTICUT CITIZENS WITH DISABILITIES
TO HAVE
A HOME OF THEIR OWN*

STATE POLICY REVIEW AND RECOMMENDATIONS

PREPARED ON BEHALF OF:

CONNECTICUT HOME OF YOUR OWN INITIATIVE

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STATE POLICY REVIEW AND RECOMMENDATIONS

I. INTRODUCTION

People with disabilities want a place to live that they can call their own. Their dreams are no different from their fellow citizens in this regard. Many people with disabilities, however, also need supports and other assistance in order to enjoy everyday community living. For these individuals, having a home of their own frequently is intertwined with the availability of natural, community and public supports to help address these needs.

Historically, public programs tied the availability of services and supports that people with disabilities need to residential facilities that provider agencies own and operate. Obtaining publicly-funded supports meant that a person must become a “resident” of a group home or other agency owned/operated living arrangement. Dollars were tied to service setting. If the person wished to have a home of his or her own, the supports often cannot follow along from the licensed residence to a “regular” living arrangement. Housing and services were welded together.

Policies and program practices are changing to support rather than work in opposition to the legitimate desire of people with disabilities to secure tenure. Service systems built around specialized residences are giving way to systems geared to delivering needed supports to people in everyday living arrangements. Over the past decade, understanding of and confidence in supporting people with disabilities outside the confines of congregate facilities has grown enormously. People who have secured tenure are telling us that it means they lead more self-determined, self-sufficient and secure lives. They have better connections to their communities.

“People with disabilities should live in homes (the typical range of dwellings) in which they have tenure (ownership or lease) and control over the environment. People with disabilities have the right to the safety and security of tenure. They should have the right to decide where they live, and with whom.”

*A Declaration of Community
Connecticut Council on
Developmental Disabilities*

The proposition that people with disabilities should be able to decide where and with whom they live is straightforward enough. Central to making that proposition a reality is that people have the wherewithal to obtain their own housing. Many people with disabilities, however, have very low incomes. This makes it difficult for them to secure a home of their own. Many people need supports (e.g., personal assistance) in order to live on their own. Public policy and programs, however, frequently limit the supports available to people who live on their own while paying out large sums when a person is served in a congregate setting. The housing costs associated with community residences frequently are heavily subsidized; similar subsidies often are not available to support people with disabilities in gaining tenure.

If people with disabilities are to realize the dream they share with their fellow citizens of having a home of their own, there must be fresh thinking about the full range of public policies that govern disability service systems and affect the ability of people to secure their own housing. Service systems must become more agile and person-centered. Helping people find and secure a home of their own must be a central focus. Home ownership is a “platform for community membership”, for promoting self-determination and self-sufficiency. It should not be regarded as an “alternative” but rather as a central tenet of public policies that affect people with disabilities.

“Support can become more personalized when it is not dictated by the rigid protocols required when many people live together in one facility. With home ownership, the agency responsible for providing support no longer owns or leases the house; the individual does. As needs change, support can be modified accordingly, in the person’s home. People are not moved when the need for a new service or support arises and are thus more able to sustain stable and typical connections to their communities. Therefore, ownership can serve as the platform for community membership.”

*Jay Klein & Merrill Black
Extending the American Dream*

Unraveling the tangle of public policies that pose barriers to people securing tenure is no simple task. It involves new thinking about how dollars are deployed in service systems and programs regulated. It also involves a shift from the “treatment and supervision” philosophy that has dominated disability policy to sponsoring new strategies for cultivating partnerships among public service systems, people with disabilities, their families, friends and allies. It means confronting the economic barriers to tenure that many people with disabilities face. New relationships among public disability and housing programs and the private sector must be forged.

In 1994, states purchased residential services on behalf of approximately 310,000 individuals with developmental disabilities.¹ Only about one in nine of these individuals lived in a home of their own. It is clear that there is a long way to go in aiding people with disabilities to secure and enjoy tenure. That journey will entail pursuing the policy changes necessary to make tenure a reality for a steadily growing number of people with disabilities.

The National Home of Your Own Alliance was created to assist key stakeholders nationwide in expanding opportunities for people with disabilities to realize their dream of home ownership. The Alliance has identified a variety of practical steps for assisting people in acquiring a home. It is working directly with several states in developing an improved capacity for supporting people in obtaining housing that they choose and control. The Alliance recognizes that acquiring and financing housing is but one facet of making a “home of your own” a reality for people with disabilities. However practically feasible home ownership might be, many individuals with disabilities will not be able to make their dream come true unless public policies that dictate the terms and conditions under which supports may be purchased also change. In many respects, securing essential changes in public policies is just as important as housing finance in enabling people with disabilities to take control of their lives.

Connecticut requested Alliance assistance in improving the State’s capacity to help people with disabilities secure a home of their own. Connecticut has launched a Home of Your Own Initiative. The mission of this initiative is to “create opportunities for people with disabilities to own their own homes and to assume control over their living situations and to ensure that home ownership is a viable housing option available to Connecticut’s citizens with disabilities who choose it”.² The initiative is a collaboration of Connecticut

state agencies, other organizations, and people with disabilities to discover how to make home ownership a reality for more Connecticut citizens with disabilities who want a place of their own.

One component of the Alliance's work with Connecticut is the sponsorship of a "policy review" to identify State policies that facilitate or impede the State's citizens with disabilities in acquiring a home of their own. The Alliance, with the concurrence of Connecticut project managers, asked Gary Smith, Director of Special Projects for the National Association of State Directors of Developmental Disabilities Services, to conduct this policy review. To that end, Mr. Smith conducted a two-day site visit to Hartford in January to meet with State officials and a variety of other interested parties to discuss Connecticut's current policies and their ramifications for people with disabilities acquiring a home of their own. In the course of this policy review, Mr. Smith also reviewed numerous documents related to supporting people with disabilities in their communities. A draft of this report was reviewed by several Connecticut Home of Your Own Initiative project participants. They offered many useful comments that aided in the preparation of the final report. Their assistance and insights are much appreciated. This report offers observations, findings, and recommendations concerning Connecticut's policies in this arena.

Connecticut's policies and how they affect people with disabilities are the focus of this report. Over the course of this review, the federal policy context in which Connecticut's programs for people with disabilities operate is undergoing momentous change. As this review was being finalized, for example, Congress is poised to end the 30-year old Medicaid program (which plays a pivotal role in underwriting long-term care and supports for people with disabilities), replace it with a "block grant" program, and turn over policy direction to the states.

It would be fool hardy to ignore these watershed changes in federal policy and their potential implications for state systems that support people with disabilities. In disability services, federal and state policies are intertwined. However, many of the proposals that have been advanced have not yet passed nor has the President acted them. The present federal policy context is extremely turbulent. In this review, we acknowledge this turbulence and, as appropriate, assess the potential implications of the proposals that are being seriously discussed for Connecticut's home of your own initiative.

II. A FRAMEWORK FOR POLICY ANALYSIS

The premises of this policy review are straightforward:

- ***People with disabilities are citizens first and members of their communities.*** As community members, people with disabilities should live, work, learn, and participate in their communities on equal footing with their fellow citizens.

- ***People with disabilities should be afforded every opportunity to live where and with whom they want.*** The fact of disability should not mean that people with disabilities face more restrictions in their choice of housing or living arrangements than their fellow citizens. Both federal and state policies affirm that people with disabilities shall not suffer discrimination in their selection of housing.

• ***Public programs should be premised on supporting people with disabilities to realize their dreams and aspirations, including having a home of their own.***

The public programs should focus on assisting people with disabilities to be self-sufficient, affirm their right to self-determination in life choices, and promote community presence and participation. These central policy values should be the starting point for crafting public programs in support of people with disabilities.

“Today, people with severe disabilities and their allies search to restore the older, deeper meanings of home and house and to extend their meaning to people who have historically been, at best, subordinate members of other men’s households”

*John O’Brien
Down Stairs That Are Never
Your Own*

• ***The separation of supports/services from housing is fundamental to ensuring that public programs operate in support of tenure.*** When the receipt of services and supports dictates that a person secure a placement in a living arrangement owned or operated by a public or private agency, he or she suffers a loss of freedom and control over his or her own life. Separating housing and supports is critical. Public programs should be structured so that supports follow the person to his or her desired living arrangement. People who live on their own should be able to access housing assistance dollars on an equal footing with service agencies.

Having a home of your own must not be regarded an extraordinary privilege that only can be extended to a few people with disabilities. Tenure is intrinsic to people with disabilities achieving community membership and exercising their full citizenship. Public policy must support and aid individuals who want a home of their own.

Our review of Connecticut’s policies is based on the foregoing premises. The review is organized around the interplay between public policy and opportunities for people with disabilities to acquire a home of their own in four distinct, yet intertwined policy dimensions:

• ***Supports Policy.*** Many people with disabilities need various services and supports in order to address the problems disability poses for them. Absent access to such supports, individuals cannot be as self-sufficient as they can or would like to be. Such supports can include skill training, personal assistance, and others. Public programs are an important source of such supports. State policies that limit the provision of services to particular types of facilities/community residences pose an enormous obstacle to many people in securing tenure. Such limitations sometimes take the form of a state’s restricting the purchase of such services to licensed, agency-operated residential settings. Other times, they take the form of a state’s locking in dollars to provider agency contracts, making it difficult for the person to move into a home of his or her own absent the “permission” of the agency. Similarly, provider agencies also find themselves saddled with restrictive requirements that prevent their shifting contracted dollars or “slots” to support people who want to live on their own.

A state’s supports policies are a critical element of the home ownership equation. Funding and regulatory policies that tie supports to specialized arrangements under the ability of people to exercise choices concerning where they live. Policies that make supports available to people on equal footing regardless of living arrangement or disability label clear the way for individuals to decide where they want to live and with whom. “Supported living” and “personal assistance” are two directions that support tenure for people with disabilities.

In this dimension of the policy review, we examine Connecticut's policies to answer the question: *“What assistance can people receive who live in a home of their own?”* We look at Connecticut programs that purchase or arrange for services and supports for people with disabilities. We point out the restrictions and contingencies related to living arrangement that might pose barriers to individuals who want to live on their own. Central to this review is looking at rules that govern the deployment of dollars, state or federal. We point out areas where policies might change in order to afford people better opportunities to have a home of their own.

- ***Income Policies*** Having a home of your own means being responsible for paying for housing and other living expenses. Most people with severe disabilities have low incomes due to barriers to their securing employment. For example, only about 10% of all federal Supplement Security Income (SSI) recipients with disabilities hold jobs. Like other low income Americans, finding affordable housing is difficult for many people with disabilities. A state's income assistance and other policies can affect how much money people with disabilities have available to meet housing and other living expenses. For example, states that supplement federal Supplemental Security Income (SSI) payments make it easier for people with disabilities to achieve tenure. However, sometimes a state's supplementation policies are discriminatory: e.g., they provide for higher payments when individuals live in a congregate setting than when they live on their own. State income policies directly affect the feasibility of an individual's meeting the ongoing expenses associated with housing.

In this dimension, we review Connecticut's policies with the following question in mind: *“What sources of income assistance are available to people who live on their own?”* We examine this question to learn about how much money people with disabilities control that can be applied to acquire their own housing.

- ***Housing Policies*** A major consideration for any individual in acquiring a home is its affordability. Affordability is affected by: (a) the amount of up-front money that a person must have in order to move in; (b) the monthly cost of the home (which is determined by the amount borrowed and the interest rate as well as taxes and insurance); and, (c) whether assistance is available to hold down these costs. There are many federal and, often times, state programs that are specifically geared toward making housing more affordable for low income individuals. Such programs include low-interest rate loans, mortgage buy-downs, and reduced rents in the form of housing vouchers. Many people with disabilities can qualify for these programs. However, frequently, they are not aware that such programs exist or have to overcome various obstacles in order to participate in them.

Hence, we ask: *“What options are available to make housing more affordable?”*

- ***Coordinating Supports and Housing*** Finally, pulling together all the pieces to make housing and supports work together can be challenging for both people with disabilities and the support system. Working through mazes of programs and their requirements can be daunting. Connections must be made to lenders. Some people with disabilities need assistance in this regard. The orientation of many service systems to congregate housing often leaves them ill-equipped to help people who need assistance in finding and pulling together what they need in order to secure tenure. A state's policies and support coordination systems often times are key ingredients in this regard.

Hence, it is important to ask the question: *“How are people connected to supports and other assistance to help them secure a home of their own?”*

If more people with disabilities are to have their own home, state policies in each of these dimensions must work in tandem to help individuals achieve their goals. Past policies must be rethought. Innovative approaches in support of people must be fostered. Traditional ways of serving people with disabilities must give way to collaborative approaches that cut across disability and agency lines to foster new partnerships.

Central to such re-engineering is overcoming various myths and prejudices that have shaped public policies that affect people with disabilities. One such myth is that it is “cheaper” to pay for congregate placements than to support a person in his or her own home. Another myth is that it is dangerous for people with disabilities to live on their own and, hence, traditional living arrangements offer better safety and security. Yet another prejudice is that people require constant supervision and training in order to achieve their “highest level of functioning”. Myths and prejudices such as these have shaped disability policy. There is mounting evidence that they have very little basis. People with severe disabilities can and, more and more, are living everyday lives in their communities. What has been realized for these individuals should become the expectation for all.

In the following sections of this report, we examine Connecticut’s policies against these four policy dimensions to assess how well they work in supporting people with disabilities to have a home of their own. We offer various suggestions concerning how the State’s existing policies might be changed in order to improve opportunities for people with disabilities to exercise their citizenship in their communities.

III. SUPPORTING PEOPLE WITH DISABILITIES IN CONNECTICUT

“What assistance can people receive who live on their own?”

Many people with disabilities need special assistance in varying degrees. Many times friends and family provide this support. Public programs also play a critical role in providing personal assistance and other supports to individuals. For various reasons, such assistance became packaged up in the form of specialized mental retardation/ developmental disabilities residential facilities, nursing facilities, board and care homes, and the like. Service systems were built around facilities in the name of “efficiency”, “clinical models”, and the premise that people with disabilities needed constant oversight. Today, the lion’s share of dollars spent for services and assistance on behalf of people with disabilities flows into facilities that are not their own.

This is changing. In mental retardation/developmental disabilities systems, service and support dollars that once flowed only to facilities increasingly are paying for assistance and support in homes where people have tenure. “Supported living” has become more common place. “Supported living” means that assistance and support is brought to where the person chooses to live. People do not have to give up tenure in order to obtain assistance. Once thought of as mainly a “model” for individuals who needed only modest supports, supported living has proven to be much more robust. People once labeled as “being too disabled” for “independent living” are enjoying everyday lives and tenure in their communities. People’s needs for supports might vary; the strength of supported living is that it can flex around those needs without having to deny people tenure.

Elsewhere in the disability community, the notion that assistance should come to people is labeled “personal assistance”. People with disabilities value personal assistance services for a simple reason: it enables them to achieve independence and self-sufficiency. Even though there are differences in terminology, both supported living and personal assistance have a similar aim in mind: bringing support to people where they live, not forcing them into specialized or congregate care facilities.

One reason why disability services became concentrated in facilities was the “institutional bias” of the Medicaid program. Medicaid dollars underwrite long-term care and support services for millions of individuals who are elderly or have disabilities. Most of those dollars flow into nursing facilities or ICFs/MR. That bias is being overcome through the rapid-paced expansion of home and community-based waiver programs as well as states placing more stress on options such as personal care. Dollars once available only to purchase institutional services are being redeployed to buy supported living and personal assistance for people with disabilities. Congress is considering changes in the Medicaid program, however, that will affect supports for people with disabilities.

Connecticut’s programs for people with disabilities are in transition from relying on purchasing services in specialized living arrangements to offering more flexible supports that are better geared to supporting individual choice concerning where and with whom to live. The State has taken several important steps in this regard. More needs to be done, both within the mental retardation service systems and in broadening the scope of supports that are available for people with other disabilities.

Our review of Connecticut’s policies concerning supporting people to live in a home of their own necessarily proceeds along agency/disability lines. As elsewhere, Connecticut has organized its public programs on a categorical rather than transdisability basis.

A. THE MENTAL RETARDATION SYSTEM

By far the largest and most distinct collection of programs that furnish/purchase services and supports for people with disabilities in Connecticut is lodged with the Department of Mental Retardation (DMR). DMR operates large facilities (such as the Southbury Training School and the regional centers) and specialized community-based residences. About one-half of the individuals who participate in the Connecticut’s supported living program are served directly by the Department. Increasingly, DMR is purchasing community residential as well as other services and supports from the private sector. DMR also purchases daytime and employment services and administers the State’s family support program. DMR has a regionalized contracting/case management system through which it manages services for people with mental retardation. Overall, DMR serves or arranges for services on behalf of nearly 13,000 individuals.

More than one-half of these individuals receive some form of residential services, furnished by DMR itself, private agencies with which the Department contracts, or in other settings (e.g., nursing facilities) that are paid for by other agencies. The scope of Connecticut’s residential services for people with mental retardation is more extensive than in most states. In 1994, Connecticut provided or purchased residential services for 170.0 persons with mental retardation per 100,000 state population versus a nationwide average of 120.6.³ Measured in this fashion, Connecticut ranked 10th among the states in terms of the number of individuals receiving residential services relative to State population. People with mental retardation in Connecticut are twice as likely to receive residential services in small (6-bed or less) community-based settings than is the case nationwide.⁴ While Connecticut has made a significant commitment to residential services for people with mental retardation, it also has a large, persistent and growing waiting list for such services, a problem it shares with the majority of other states.⁵

About one of every seven people with mental retardation who receive DMR-funded residential services participate in the supported living program: e.g., they receive supports in a living arrangement they have chosen and are responsible for rather than in an agency-operated specialized facility. As noted earlier, nationwide only one in nine individuals who receive publicly-funded residential services are being supported in their own homes. DMR's track record in supporting individuals in their own homes is stronger than that in most (but not all) other states. The State's supported living program is only a few years old. It has grown briskly to where today over 900 individuals participate in the program. Supported living has helped change the direction of DMR's residential service system from nearly exclusive reliance on agency owned and operated residences. Changes have been made in Connecticut's Medicaid home and community-based waiver program in order to access federal financial participation in the cost of supported living services.

DMR defines supported living services as "opportunities for persons with mental retardation to live in their own homes and apartments and receive necessary individualized supports. Individuals may live alone or with roommates". In supported living, people pay for their own living expenses; some receive additional assistance to meet these costs in the form of a housing subsidy from DMR. However, this option "*is limited to those individuals who do not require ongoing supervision or the presence of overnight staff*". Including housing subsidies and support services, payments for supported living run about \$86/day. In contrast, average payments to licensed Community Living Arrangements (CLAs) (most of which serve six or fewer individuals) are roughly three times as high.

Supported living services are obtained via contract with private providers or furnished/arranged for directly through the DMR regions. Supported living is subject to DMR regulation but not licensed. Supported living services are described in DMR guidelines as complementing other natural and community supports. Any of a wide range of supports may be furnished to individuals and these supports may be furnished by a wide range of individuals (including neighbors, roommates, companions, personal assistants and so forth). DMR's supported living guidelines allow individuals to live in a variety of housing options. The person may rent his or her living arrangement from the supported living provider or obtain housing directly. DMR housing expense subsidies are available (although limited by appropriation) to assist a person to "meet the housing costs attributable to the acquisition, retention, use and occupancy of a personal home in the community". Such costs can include rental payments, security deposits, utilities, and liability insurance. Housing subsidies are coordinated with the income a person receives to arrive at a net subsidy amount.

The DMR's supported living program provides a good foundation for expanding opportunities for people with mental retardation to have a home of their own. The Department's supported living guidelines are consistent with the basic, essential principles of supported living: individual choice of living arrangement, flexibility in the types of supports people may receive, and the separation of the delivery of supports from housing. The program has grown relatively quickly, providing an indicator that it is an option that has found an eager market.

"Our current array of service options typically offers 'all or nothing' options. People served by the department generally receive comprehensive services in DMR-funded sites or limited case management and individual and family support services in their own homes. We need to expand the options and develop more personalized supports that allow people to live and work in places where responsibility for providing necessary supports is shared by the department, community agencies, associations, ordinary citizens, and significant people in the life of the person with mental retardation."

*Connecticut Communities Include...
Department of Mental Retardation*

In Connecticut, the central questions with regard to support policies and their implications for home ownership for people with mental retardation lie in how supported living might be strengthened and expanded in order to provide more individuals with the opportunity to participate in the program. The advent of supported living has helped reduce the State's reliance on serving people in agency owned and operated facilities. This is a positive step. Still, most people served by the Department reside in homes and facilities that are not their own. Connecticut should consider policy changes and other strategies aimed at converting supported living from one among many residential service options to the standard for assisting individuals to enjoy everyday living in their communities. Suggestions along these lines are offered below.

B. SERVICES AND SUPPORTS FOR PEOPLE WITH OTHER DISABILITIES

In contrast to people with mental retardation, Connecticut citizens with other disabilities have had more limited access to publicly-funded supports to assist them in living in a home of their own.⁶ Most of these supports are furnished through the Department of Social Services, employing state general revenue and Social Services Block grant funds. Medicaid dollars have been used mainly to pay for home health aide services for individuals with other disabilities. However, during its 1995 session, the Connecticut Legislature approved the development and submission to the federal Health Care Financing Administration of an HCB waiver program that would furnish personal assistance services to people with disabilities.

For most people with disabilities other than mental retardation, the majority of direct assistance they receive from the State takes the form of income assistance supplements to federal SSI payments and home health care services through the Medicaid program. Most Connecticut people with disabilities who receive assistance rely on home health agencies to meet their support needs. Unfortunately, this means that people must use home health aides selected by an agency; they have no role in supervising these aides; and, they have little to say in scheduling or planning what these aides will do. While home health services can play a role in meeting the support needs of some people with disabilities, they are relatively narrow in their scope and usually more expensive than other options.⁷

Connecticut earmarks only limited non-Medicaid dollars directly for personal assistance services for people with disabilities. People turn to home health because it is what is available rather than what they would prefer. Some people are aided by the Community-Based Services Program (a.k.a., "essential services") that furnishes in-home services to about 2,000 individuals but only has \$7.5 million in funding (state general revenues and federal Social Services Block Grant dollars).⁸ The Personal Services Program (PSP) has been in operation since 1989. This is a "direct pay, consumer-directed PAS program".⁹ It is funded with (and limited by) state general revenue dollars.

The Personal Care Assistance Program (nicknamed the Working Persons' Program) uses state funding to serve a limited number of people who work at least 17 1/2 hours a week. Under this program, people with disabilities receive a check each month which they use to pay their assistants. The only criteria, other than employment and some broad income guidelines, is that the person must require "hands-on" assistance. People can hire their own assistants, decide what their employees will do, and negotiate the wage rate paid the assistant. Each person works out a budget according to the money available and how many hours of assistance are needed. However, there only is limited funding for this program (only about 50 people can be served statewide and the maximum grant is \$7,300 a year). Even though this is a small program, it is highly regarded because individuals can tailor supports to meet their needs.

The lack of distinct, full-fledged programs in Connecticut to support people with disabilities in their own homes stands in sharp contrast to the State's funding of services for people with mental retardation and home care for elderly persons. For example, the Connecticut Home Care Program for Elders serves roughly 6,000 individuals.¹⁰ The program blends state and Medicaid dollars (via the home and community-based waiver program) to furnish supports for elderly individuals who are at risk of nursing home placement. The Home Care Program is the result of consolidating separate programs into a more seamless approach to meeting the needs of elders in their own homes.

In 1994-95, an interagency task force sponsored by the Department of Social Services conducted an in-depth look at how Medicaid dollars might be employed in order to broaden the availability of personal care/assistance services for people with disabilities. The task force weighed the pros and cons of the State's adding the full-blown coverage of personal care services to its Medicaid program.¹¹ Ultimately, the task force recommended¹² that Connecticut develop and submit a request to the federal Health Care Financing Administration to launch a home and community-based waiver program that would offer personal care assistance services to Medicaid recipients with disabilities.¹³ During its 1995 session, the Connecticut Legislature gave the Department of Social Services the go ahead to submit this request. The HCB waiver program is being fashioned to support 409 individuals at a total estimated cost of \$8.5 million. The program is structured to be budget neutral (e.g., it will be financed by reprogramming current dollars to serve as matching funds). The aim of the HCB waiver program is to expand the availability of consumer-directed personal assistance programs. Work also has been underway on developing a home and community-based waiver program for individuals who have an acquired brain disorder.¹⁴

For many people with disabilities other than mental retardation, the availability of personal assistance services is a key ingredient in their achieving independence. Tenure is very much tied to their being able to access and direct reliable supports. The largest source of assistance presently in Connecticut for people with disabilities is home health. Home health services embody a "medical model" that addresses only one aspect of the supports people need to function independently. Home health services are expensive; like other medically-oriented services they are treatment-based and clinical in nature. The present reliance on home health services stems in part from their availability rather than their necessarily best meeting the needs of many people with disabilities. Clearly, personal assistance is the preferred alternative, but only limited state dollars have been available to pay for this option.

The planned HCB waiver program is a step in the right direction. The HCB waiver program is inherently more flexible and susceptible to consumer direction. The program does not need to operate under a medical model. The waiver program can serve as a stepping stone to offering personal assistance to people with disabilities on a wider basis in Connecticut.

C. FEDERAL POLICY CHANGE

Before turning to a discussion of policy changes that Connecticut might entertain to expand the availability of supports for people with disabilities that would enable more individuals to have homes of their own, it is important to recognize that major federal policy changes are on the horizon. Because the Medicaid program plays such a large role in helping underwrite long-term care and supports for people with disabilities, these changes cannot be ignored. For example, nationwide, state and federal Medicaid dollars help underwrite HCB waiver and ICF/MR services for nearly 300,000 people with

developmental disabilities at an estimated 1995 cost of \$13.5 billion nationwide. These dollars play a pivotal role in Connecticut in helping to pay for services for people with mental retardation. The HCB waiver program has the capability of underwriting personal assistance services for people with disabilities. A state's ability to pay for long term supports for people with disabilities is intertwined with (and frequently restricted by) federal Medicaid policies.

The Medicaid program has permitted the states to tap into open-ended federal dollars to pay for a share of the costs of meeting the health and long-term care needs of its low income citizens. In the arena of long-term care/supports, Medicaid dollars pay for the bulk of institutional services. The enactment of the home and community-based waiver program in 1981 gave states the ability to redirect dollars that would be spent on institutional services to purchase a wide array of community services and supports. Presently, the states operate 200+ HCB waiver programs that serve individuals who are elderly, people with developmental disabilities, and individuals with other disabilities. Spending for HCB waiver services has been growing very rapidly in recent years; indeed, it is the fastest growing component of the long-term care sector of the Medicaid program. States for both strategic (HCB waiver services are less costly than institutional services) and programmatic reasons (HCB waiver services can be better tailored to meet individual needs) have seized upon the HCB waiver program as their preferred Medicaid financing option. As a result, the number of persons served in nursing facilities has not been growing and the number of individuals placed in ICFs/MR has declined nationwide.

As part of achieving the goal of balancing the federal budget by the year 2002, Congress adopted a budget resolution in June to reduce federal Medicaid outlays by \$182 billion over the next seven years. More recently, the House Commerce and Senate Finance Committees approved measures (which ultimately are to be folded into an omnibus Budget Reconciliation Act) to secure this reduction. While there are key differences in the measures, their overall thrust is similar. Namely:

- Present federal Medicaid statutes (Title XIX of the Social Security Act) would be replaced by an entirely new Title XXI of the Social Security Act.
- Under Title XXI, states would receive federal dollars in order to provide health and long-term care services to their low income citizens. However, the amount of federal dollars would be capped nationally and on a state-by-state basis rather than remain open-ended.
- Each state would receive an allotment that starts with what it is presently spending for Medicaid services; in the future, each state would be guaranteed an annual increase of at least 2%. Based on complex formulas, a state's allotment could increase at a higher percentage rate, subject to a maximum.
- Existing federal statutory and regulatory requirements concerning Medicaid would be dropped in favor of permitting each state to set up its own program, including deciding which citizens would be eligible to receive services, what services would be offered (including offering different services to different groups), and how much to pay for services. States could restrict eligibility to current Medicaid eligibility groups or could simply tie eligibility to a purely income-based means test. A state would set out its program in a "state plan" which would describe the state's goals and objectives, how it would spend its allotment, populations covered and services offered.

- The proposed legislation lists a wide range of health and long-term care services that a state might offer under its plans. Included are home and community-based services as well as community supported living arrangements services. The decision of what services (and their scope) would be offered would be left up to the states.

The thrust of this proposed legislation is to give the states a free-hand in designing and managing health and long-term care services for low income individuals and families. The quid pro quo for this flexibility would be an end to the present open-ended entitlement to federal Medicaid dollars.

As this report was being finalized, these proposals had not been passed by either the full House or Senate nor their differences resolved nor approved by the President. Changes to the Medicaid program will be part of a larger measure that includes changes to the Medicare program, tax policy, and other changes in federal policy. There is great controversy about all these proposals; undoubtedly, they will change during the give and take between the Congress and the President. Most observers do not expect resolution until December (and possibly later).

While it would be foolhardy to predict the ultimate outcome of this particularly turbulent and highly charged debate concerning federal policy, it would be equally foolish to ignore the strong potential that Medicaid in its present form will end. Most observers believe that the Medicaid program will be capped and ultimately turned over to the states (albeit, probably with more “strings” than contained in the present House and Senate proposals).

What does all this mean for disability programs that rely on Medicaid dollars to pay for long-term supports? There are several implications that merit discussion:

- The spending limitations that have been proposed are well below the recent 11% rate at which Medicaid spending for long-term care services and supports has been growing in recent years. By 1998, the increase in federal payments to the states would fall to 4% and maintained at that level through 2002. The overall effect of the proposals as they stand now is to reduce federal outlays by about 18.5% over the next seven years; by the year, 2002 outlays would be 30% below the levels projected under current law. Obviously, states will not be able to sustain current growth rates in long-term care services.
- Medicaid spending caps have two implications. First, obviously, strategies to “leverage” or “maximize” Medicaid dollars would no longer be relevant. Second, federal assistance to the states would be decoupled from: (a) changes in the number of Medicaid recipients; and, (b) changes in the cost of services. Under present policy, both factors are accommodated through open-ended federal financing. Many observers are concerned that the caps laid out in the Congressional proposals are so low that states will have little choice but to drop services or cut back on who would be eligible for services.
- The proposals eliminate current mandates in terms of the services that a state must offer and who, at a minimum, must be served in a state’s program. These policy decisions would be made by the states. While the proposals ultimately may change to restore some basic mandates, states likely will have far more flexibility than is presently the case.

- With respect to particularly the ICF/MR and HCB waiver programs, the proposal would end federal standard setting for ICFs/MR (in favor of states adopting their own standards or employing accreditation) and would eliminate the need for a state to seek federal approval of an HCB waiver program. HCB services could be offered by a state under its plan. In addition, a state may offer community supported living arrangements services (an option that had been restricted to eight states under a pilot program approved in 1990). Generally, states would be free to craft their coverage of HCB and related services as they see fit. Similarly, a state could offer personal assistance services on the terms it decides.
- Both proposals open the way for states to expand the use of managed care options without having to obtain special federal waivers. States would have a free hand in restricting recipient freedom of choice to select a provider, a restriction that today requires the approval of a special federal waiver. States will be able to channel recipients to managed care plans. Many observers believe that expanding the use of managed care will be one of the principal ways that states seek to contain Medicaid outlays in order to remain within their federal caps.

For disability programs, it is particularly important to point out that:

- Decisions about how much of a state's allotment to spend on long-term supports will be caught up in the larger calculus of how a state plans to restructure its Medicaid program to live within the federal cap. States can make decisions to allot more or less money to long-term supports. Their willingness to do so, however, will depend on the decisions concerning health care and facility-based long-term care programs. Neither proposal guarantees or requires that a state maintain its present level of outlays for long-term supports.
- Mental retardation/developmental disabilities systems have been able to maintain a relatively high rate of growth over the past several years by progressively leveraging more and more federal Medicaid dollars, particularly through the HCB waiver program. Systems have expanded at a pace faster than underlying increases in state general revenue appropriations. This leveraging strategy (which some states already have exhausted) will no longer be relevant. Absent infusions of state tax dollars or other changes, the funding available to MR/DD systems today may well represent a high-water mark for the foreseeable future. Given the waiting lists for services that many states have, this flattening of the revenue growth curve has serious implications.
- Much the same can be said in relation to other populations who need long-term care and supports. As it presently stands, state funding caps would be based on either 1994 or 1995 spending levels. This means that efforts a state may have underway to boost federal Medicaid revenues may go for naught.
- The proposals also would give states latitude to restructure their present programs. This flexibility has its pros and cons. Some observers are concerned that states will simply use this flexibility to cut payment rates or eliminate services. The other side of the coin, however, is that this flexibility can open the way to fundamental program restructuring that is not possible today due to rigidities in federal funding, particularly given its categorical nature. Some policy barriers that prevent states from shifting dollars from institutional services to community-centered supports would be eliminated. States potentially would have far greater ability to manage their long-term care budgets on a global basis, including better ability to promote cross-cutting, transdisability support strategies.

- The flexibility afforded states also could clear the way for wider use of vouchers and similar tools that enable individuals to exercise greater self-determination.

The changes being contemplated by Congress potentially have very serious implications for the future funding of disability programs. Systems that today struggle under the pressure of maintaining current services while responding to new demand would be under even more pressure in the future. How disability programs might fare as states realign their Medicaid programs to live within federal caps will be decided at the state level within the larger context of state health and budgetary policy. In the past, state systems relied on leveraging strategies to increase federal funding. In some senses, this has meant that they did not compete with other elements of the Medicaid program for dollars. Under the Congressional proposals, this would no longer be true.

Acknowledging the peril and uncertainty that attends what is no less than a watershed change in federal policy, the proposed restructuring of the Medicaid program also opens the way to states to rethink their entire approach to serving people with disabilities. Old ways of doing business can give way to entirely new approaches. Federal Medicaid policy, as presently constituted, does create barriers to various strategies (such as vouchers) that many believe are vital to promoting greater independence and self-determination for people with disabilities. Each state will need to give serious thought to how it might take advantage of this new flexibility. Most clearly, a good deal of this rethinking needs to be devoted to promoting strategies that allow dollars to be employed as productively as possible in order to mitigate the effects of the spending caps. Shifting from higher cost to lower cost services is one such strategy. The more exciting possibilities lie in establishing an environment where dollars can be more readily combined with other resources and thereby displace the present “all or nothing” framework of the Medicaid program.

If the proposed changes emerge largely in tact over the next few months, it will be enormously important for all stakeholders to take a serious look at how this flexibility can be employed to best advantage. Doing the same, only less is one response. Changing the basic ground rules is another.

With regard to this project and this policy review, the proposed changes have narrow implications (e.g., Connecticut will be able to more readily change its present mental retardation waiver program to include options described below if it chooses). They potentially also have broader implications (e.g., enabling the direct cash reimbursement of individuals for personal assistance services). It also is important to keep in mind that whether under the current Medicaid program or a substantially different “Medigrant” program, sound strategies must undergird any program. The present HCB waiver program is very flexible; under the Congressional proposals, this flexibility will be enhanced even more. Flexibility, however, does not translate directly into sound practices. Good design based on fundamental agreement concerning program aims always is the best first step.

It is too early to tell how the changes Congress is contemplating might directly affect aspects of home ownership not directly related to furnishing supports to people with disabilities. Under present federal policies, for example, Medicaid dollars can be employed to pay for the housing costs associated with operating an ICF/MR but (with some exceptions) cannot be used to meet the same costs for people who participate in an HCB waiver program. It is unclear whether a state could routinely use federal dollars to pay for a portion of an individual’s housing costs or not. What is clear is that states can continue to do what they do today and will have increased opportunities to pursue strategies that are off-limits today.

In the following discussion of strategies that Connecticut might pursue in order to strengthen the availability of supports to people with disabilities that will aid their securing tenure, we frame some strategies in the context of present federal policy but also point out some of the implications of the federal policy changes that are under consideration.

D. STRATEGIES RELATED TO SUPPORTED LIVING/DMR SERVICES

Clearly, in terms of increasing access to supports and assistance that enable individuals with mental retardation to secure tenure, expanding the role that supported living plays in DMR's service system must be the focal point. Along these lines, strategies and policy changes should be considered in the following areas:

- **System Development.** Experiences elsewhere bring to the fore the importance of building confidence and competency in supported living across all sectors. Changes in state policies contribute to but do not necessarily result in a climate where supported living can flourish. There are steps that a state can take to aid in creating such a climate.
- **System Conversion.** Similarly, there are other steps that a state may take that encourage and support existing vendor agencies to re-engineer the services they presently provide to transition to supported living. This re-engineering should be based on inviting — rather than mandating — the active participation of agencies interested in conversion.
- **Payment Policies.** Often times, a state's payment policies pose real obstacles to establishing a level playing field between supported living and other residential service options. Often, these policies need to be modified, else individual choices are foreshortened.
- **Medicaid Policies.** State mental retardation/developmental disabilities systems are enormously reliant on Medicaid dollars. If Medicaid dollars are not available to pay for supported living, it is highly unlikely that supported living will flourish. To this end, how a state employs its home and community-based waiver program to pay for supported living is critical. The proposed Congressional changes to the Medicaid program will eliminate the need for a state to obtain a waiver or federal approval.
- **Regulatory Policies.** How a state regulates its service system strongly influences the scope and nature of the services and supports available to individuals. Supported living succeeds when it is highly personalized. Establishing a regulatory environment that at once fosters flexibility but recognizes the need for people to have personal security is a key element in building confidence in and acceptance of supported living.

With the foregoing in mind, we offer various suggestions concerning how Connecticut might productively expand supported living opportunities for people with mental retardation.

DMR should focus its community residential development efforts on the expansion of supported living opportunities.

The Department's current long range plan recognizes that the State should shift the focus of its community options development efforts from "comprehensive" to supportive options. In the realm of residential services, this should take the form of expanding supported living opportunities. In light of impending changes in federal Medicaid policy, states must emphasize strategies that concurrently reduce reliance on "comprehensive service models" such as ICFs/MR or similar arrangements in favor of focusing on community partnership/membership options such as supported living.¹⁵ This shift already has begun in Connecticut and elsewhere. In order to meet the challenges posed by federal budget cut backs, it will be vital for states to accelerate this shift.

In this vein, DMR should make expansion of supported living opportunities its top priority. The effect of Congressional changes to the Medicaid program will be to plateau the dollars available to pay for supports for people with disabilities. Unless states shift their emphasis to shared supports (partnership/membership models), waiting lists are likely to grow longer.¹⁶

Second, Connecticut should sponsor a collaborative approach to active learning and technical assistance in supported living.

Retooling a service system around partnership/membership models requires an ongoing investment in system change activities over an extended period of time. In order to be successful, such system change efforts must engage key stakeholders in active learning across a wide range of topics in order to build a common vision of supported living and how it can promote community membership on behalf of people with disabilities. Lessons learned should be spread through technical assistance. Florida's Supported Living Project serves as an excellent, successful example of this approach. Partly underwritten with funding from the Florida Developmental Disabilities Planning Council since 1988, the Project has enabled Florida to develop a particularly coherent, shared approach to supported living. Connecticut should consider a similar step.¹⁷

Establishing a long-term supported living collaborative is essential to cultivating confidence and competency in supported living. A broad-based collaborative — composed of provider agency representatives, people with disabilities, family members, advocates and state officials — can both bring focus to supported living along with the necessary diversity of views to help ensure that the program meets the needs of all stakeholders. The collaborative approach also instills a sense of "ownership" in the program. For example, Michigan's Community Supported Living Arrangements (CSLA) program was designed under such a cooperative approach. The State's Advisory Committee continued to play a very active role over the four years that the program was in operation. While federal Medicaid funding for this program will end on September 30, the Advisory Committee assisted the Department of Mental Health in crafting changes to the State's home and community-based waiver for people with developmental disabilities so that supports could continue for CSLA participants by incorporating "lessons learned" into the waiver program. In Michigan, a supported living "community" has emerged that has resulted in broadening confidence in and stepping up enthusiasm for supported living.

This collaboration should be an integral element of DMR's strategies to expand supported living opportunities for people with mental retardation. One step that the Department should consider is the appointment of an advisory committee with many of the duties and responsibilities that similar bodies hold in Michigan and Florida. The Department should charge this committee to continuously identify policy and other changes that would yield increased supported living opportunities. The committee also

should be empowered to sponsor conferences and workshops on supported living in order to provide networking and learning opportunities for all parties interested in this topic. Finally, the committee should be a source of technical assistance to provider agencies throughout Connecticut that are interested in converting more of their operations to supported living.

If supported living is to play a larger role in meeting the needs of Connecticut citizens with mental retardation, various steps should be considered to place the program on sounder footing.

Supported living emerged in Connecticut as a way to break away from exclusive reliance on the more highly regulated, conventionally-structured Community Living Arrangements (CLA) model in order to foster alternatives that would avoid the panoply of DMR licensing rules. Supported living was distinguished from CLA by drawing a boundary between the two living arrangements; this boundary has been defined by whether an individual requires “continuous supervision/round the clock staffing.” People who need continuous supervision are deemed to be living in a CLA and, consequently, their living arrangement must be licensed. As originally conceived, it was expected that supported living would serve as an alternative to group home (CLA) placement for people who needed only more intermittent services.

Not surprisingly, supported living in some regions is pushing up against the definitional boundary. It is entirely understandable (and not unprecedented¹⁸) that some agencies are stretching the limits of supported living in order to furnish more flexible supports than might be possible under CLA regulations. Supported living “programs” frequently evolve in this fashion. Connecticut’s basic definition of supported living is appropriate. However, the boundary line between “supported living” and “CLA” services is artificial. The mere fact that an individual might need intensive supports throughout the day should not result in any fundamentally different approach to supporting the individual or in regulating the living arrangement. In other words, the principles should remain the same even though individuals might need different amounts and types of supports.

DMR has attempted to monitor the quality of supported living through the enforcement of the individual contract provisions that are crafted on a person-by-person basis. However, DMR quality assurance staff are uncertain whether essential health and safety issues are being addressed consistently. While DMR officials rightly have been reluctant to apply standard facility-based regulatory approaches to supported living, there is uncertainty concerning what approach Connecticut should take in ensuring and enhancing the quality of supported living. Finally, as supported living has grown, there also have emerged questions concerning how to structure payments to ensure economy and efficiency in service delivery.

In one fashion or another, these issues (and others) need to be addressed constructively if supported living is to be employed more broadly for people with mental retardation in Connecticut. If more people are to enjoy a home of their own, all parties must be confident that supported living is on sound footing. The program’s present framework ought to be revamped to provide greater clarity. In this regard, we recommend that DMR officials pursue in collaboration with other stakeholders a multi-faceted strategy that includes the following:

- ***First, the regulatory trap that Connecticut finds itself in must be overcome.*** Supported living should not be defined by supervision or support requirements. So defined, who may live in a

home of their own and obtain public supports is immediately limited. Instead, supported living should be simply redefined as furnishing person-centered assistance and supports to people who live in their own home without qualification as to the need for supervision. When supervision tests are used to define supported living, an artificial barrier is created. It should be kept in mind that many individuals who at first may require extensive supports (including round-the-clock assistance) will be able to function well with diminished levels of supervision after they have made connections in their communities and have had the opportunity to live on their own. If people cannot participate in supported living because they initially and even for some considerable period of time need intensive assistance, they will not have the opportunity to enjoy having a home of their own. Qualifying supported living by reference to supervision requirements traps individuals in the “readiness model”. If the current trap is solely regulatory, it should be dealt with directly. If statutory, then DMR needs to prioritize the necessary statutory revisions (including potentially the adoption of a separate statute regarding supported living as has been done in Maryland and other states).

- ***Second, Connecticut should develop and implement a more structured approach to the provision of supported living.*** Supported living in Connecticut emerged as an alternative to traditional residential models. Program guidelines are very flexible. However, the program is loosely structured and, consequently, there is uncertainty concerning the quality of supports being furnished. Rightly, any “new way of thinking” should go through an incubation period before superimposing a more structured set of policies. The time has come in Connecticut to put into place a more definitive set of supported living policies. In some respects, the State’s supported living policies describe more what it is not than what it should be.

A sound policy framework for supported living will include provisions that:

- Mandate the use of person-centered processes through which individual support strategies will be developed. Such provisions should ensure that proper attention is paid to each person’s needs for personal assistance, functional skills training, social supports, and assistance in participating in community activities. While it is not necessary to specify the specific type of person-centered planning/assessment tool an agency must use, it is appropriate to mandate that agencies/service coordinators organize support strategy development in a fashion that consistently addresses such needs. In other words, DMR’s policies should be sufficiently prescriptive to ensure that whatever process is employed in developing a support strategy will have taken into account fundamental considerations and that the resulting support strategy be responsive to identified needs;
- Require that each person’s support plan spell out the responsibilities of agencies that are to furnish supports and the mechanisms for ensuring that they are being carried out;
- Ensure that critical issues concerning personal security are acknowledged and adequately addressed. Such provisions can include mandating the use of a check list that contains descriptions of fundamental personal security issues and requires that the support agency describe how they will be addressed if they are relevant to an individual’s situation;
- Provide for continuously gathering information regarding participant satisfaction with the supports that they are receiving and ways for participant’s to voice their concerns. This can be accomplished via the State’s case management system or through alternative arrangements, including community monitoring teams, friends, family members, and so forth;

- Give the individual an unambiguous, clear role in hiring and firing support agencies and workers;
- Validate that the person is exercising real choices on an ongoing basis. A critical component of such a policy framework lies in support strategy development. A resolute commitment to the principles of person-centered planning (rather than traditional interdisciplinary team models) is absolutely critical to ensuring that supports are responsive to the needs and preferences of individuals.

In this vein, we strongly recommend that DMR officials and other stakeholders take a close look at Florida's supported living policies¹⁹. We also believe that it would be worthwhile to take a close look at Michigan's policies for its Community Supported Living Arrangements program. Michigan's track record in implementing a vigorous supported living program under the CSLA authority has been particularly noteworthy. In our view, both Michigan and Florida have done an excellent job in crafting policies that have spawned excellence in supported living.

- *Third, concerning payments and rate setting, it is strongly recommended that Connecticut adopt an individualized approach that is based directly on each person's support plan.* Kansas, Missouri and North Dakota have implemented such an approach. Payments for supported living are based on the support patterns contained in each person's support strategy. As support needs change, so do payments. Basing payments on support plans is a sensible payment approach that continuously validates and reflects the outcomes of the person-centered planning process. These individualized rate setting systems contain appropriate safeguards against excessive administrative charges while concurrently recognizing reasonable agency program management expenses. We believe this approach is superior to Connecticut's present methodology of negotiating payment rates with provider agencies. This approach supports variable daily rates based on current and future individual support needs.

DMR should work with and actively support agencies that are interested in converting CLA and other residential service options to supported living.

The advent of and expansion of supported living services has aided in breaking down some of the rigidities in the State's current residential services system. However, if supported living is to become a reality for more and more people with mental retardation, DMR also should encourage the conversion of existing CLAs to supported living. Nationwide, the expansion of supported living opportunities for people with developmental disabilities has occurred in two ways: (a) earmarking expansion dollars for supported living; and, (b) the voluntary conversion of existing community residences to supported living.

The voluntary conversion of community residences arises from the interest that many agencies have in restructuring the services they furnish to people with developmental disabilities to the partnership/membership model. Often times, provider agencies are frustrated at being locked into conventional service models. Nationwide, there is a clear movement among service providers to convert to supported living. Operators of large and small ICFs/MR have closed facilities and restructured their operations. Group home operators also have converted operations. Such conversions have been greatly facilitated by the availability of Medicaid home and community-based waiver program dollars. When ICFs/MR

convert, Medicaid ICF/MR dollars can be shifted to the HCB waiver program. When HCB waiver-funded group homes convert their operations, federal dollars can be reprogrammed to buy supports for former group home residents in their new living arrangements. Congressional proposals to restructure the federal Medicaid program will give states even greater flexibility along these lines.

To create a “conversion friendly” climate in Connecticut, DMR should request that the Connecticut Legislature alter its appropriation practices²⁰. Currently, line item appropriations are made by type of residential setting. Dollars cannot be transferred among settings without DMR’s returning to the Legislature with budget amendments or requests. The present line item appropriation structure is a barrier to DMR’s ability to manage total community residential resources in a flexible fashion. DMR should request that the Legislature collapse the current line items into a single community residential services appropriation or that the Legislature enact appropriation proviso language that gives DMR the authority to transfer funds among appropriations under prespecified conditions (including program conversion). Absent the ability to manage the residential services budget on a global basis, it will be difficult for DMR to work collaboratively with agencies interested in changing their operations.

The second step in creating a “conversion friendly” environment would entail DMR’s issuing a standing solicitation for provider agencies interested in converting to submit proposals to the Department that spell out how a conversion would be accomplished along with a detailed conversion plan/budget. Such a solicitation should be drafted to encourage agencies to lay out their preferred conversion strategy rather than prescribing the contents of the plan. DMR should require that such plans reflect the input of individuals who are affected by the plan (and their families) and show evidence of a well-considered approach to accomplishing the conversion. The conversion plan should be budget neutral. Agencies should have the latitude to identify changes that DMR might need to make in its payment processes to facilitate the conversion process (including altering payment schedules to accommodate agency cash-flow requirements). Agencies also should be encouraged to identify waivers of DMR regulations that might be needed in order to facilitate the conversion process so long as the agency spells out appropriate alternative safeguards. If the agency’s proposal identifies that an expected outcome of conversion will be the capacity to serve additional consumers, DMR should ensure that contracts will be modified to reflect that outcome rather than reduced in order to capture the estimated savings.

In addition, DMR should establish a team that is available to work with agencies that may need assistance in developing conversion plans. Such a team might be composed of DMR staff and volunteers from other community agencies that already have gone through the conversion process.

Establishing a “conversion friendly” environment is a non-confrontational, assistive step that a state can take in order to expand supported living opportunities for individuals who are presently receiving community residential services in more traditional, provider-controlled living arrangements.

Connecticut should consider changes in its Medicaid home and community-based waiver program for people with mental retardation that will assist people in obtaining the supports they need and having a home of their own in the community.

The Medicaid home and community-based (HCB) waiver program has emerged as an enormously important tool for states interested in expanding services and supports for people with mental retardation and developmental disabilities. Via the HCB waiver program, states have been able to correct the historical institutional bias of the Medicaid. Dollars that would otherwise pay for services in ICFs/

MR can be reprogrammed to purchase a wide array of flexible, community supports. States have great flexibility in designing HCB waiver programs, both in terms of the services/supports they offer to participants as well as the overall scope of their programs. In 1995, more people with developmental disabilities are receiving supports through the HCB waiver program than are served in ICFs/MR of all types. Nearly all states now are employing the HCB waiver authority as their principal tool for accessing federal assistance for community services and supports.

Connecticut began its HCB waiver program for individuals with mental retardation in 1987. The program presently serves about 2,500 individuals and brings in roughly \$65 million in federal Medicaid revenues for community mental retardation services. Until 1994, DMR principally employed the HCB waiver program as a tool to pay for traditional CLA and CTH services. In 1994, the federal Health Care Financing Administration (HCFA) approved an amendment to (a) add the coverage of additional services (including family training, environmental modifications, and respite care); and, (b) provide that waiver services may be furnished to individuals who live in their own or the family home.²¹

At present, Connecticut has renewed its HCB waiver program for persons with mental retardation for the five year period effective October 1, 1995. In its renewal application, the State continues the services offered under its present program and would to expand the number of program participants by a modest number. Under its current program, Connecticut is limited to serving roughly 3,750 individuals. The renewal request provides for the addition of approximately 600 additional persons over the next five years. Since actual utilization has been below the program's current limit, the State already has substantial latitude to expand its program. Relative to other states, Connecticut serves more people via its HCB waiver program than most (although at not quite as high a level as most other New England states). Once the State works in its coverage of supported living services under the waiver program, utilization will increase. The previous restriction of only covering CLA/CTH residents imposed an artificial cap on the number of participants.

Connecticut's HCB waiver program was designed as and remains a financing tool for the State's underlying mental retardation service system. The services and supports offered in the HCB waiver program incorporate generic DMR service definitions. When DMR spends money on a service that is pre-qualified for HCB waiver funding, it establishes a claim for a federal Medicaid payment. The dollars recovered through such claims are turned over to the State's general revenue fund. While DMR's ability to access additional federal Medicaid dollars via the HCB waiver program is taken into account by the Legislature when it makes appropriations to the Department, increased HCB waiver federal Medicaid recoveries do not necessarily translate into expanded resources for the Department. Connecticut's HCB waiver program for people with mental retardation does not function as a "distinct" program. DMR's policies define the system; the HCB waiver program helps finance the system.

Along these lines, the role that the HCB waiver program plays in Connecticut has parallels in other states. However, in some other states, legislatures have given executive agencies greater incentives to expand HCB waiver programs and the availability of Medicaid reimbursement through the HCB waiver program has been more influential in the development of such options as supported living.

In recent years, DMR has made strides in reorienting Connecticut's mental retardation system from "treatment"-oriented service models to partnership/membership approaches to supporting people in the community. The 1994 HCB waiver amendment illustrates how federal financing can change in tandem with underlying changes in a state's program.

Earlier, we recommended that Connecticut consider several changes in its supported living program to put it onto sounder footing. Will such changes affect Connecticut's ability to pay for supported living services through the HCB waiver program? The simple answer is no. There are now many states that offer supported living services on a flexible, person-centered basis without restrictions related to the "need for supervision". It is increasingly common for states to encourage the use of person-centered planning methods to drive supported living strategies. There are no particularly problematic federal barriers to a state's qualifying value-based, person-centered supported living services for Medicaid reimbursement via the HCB waiver program. This means that Connecticut can work through changes in its program supported living program with an eye toward sound program design rather than crafting its strategy based on concerns about how the "feds" might react. Also as discussed earlier, the HCB waiver program gives Connecticut the latitude to pursue the conversion of CLAs to supported living. Medicaid dollars are readily transferable from one setting to another.

Should Connecticut further amend its waiver to break out supported living as a separately covered service? Many states have taken this approach. Connecticut's HCB waiver program for people with mental retardation classifies supported living as a "residential habilitation" service. In most respects, there is little to be gained or lost by the State's continuing its current practice. The more important consideration is that Connecticut define its supported living program in a satisfactory fashion regardless of how it might be classified in its waiver program. However, making supported living a distinctive coverage frequently is useful in underscoring its importance.

There are two changes to its HCB waiver program that Connecticut should consider that are particularly relevant to aiding waiver participants in obtaining a home of their own. Each of these are examples of how the waiver program can be employed in order to aid people in obtaining a home of their own. Last year, Minnesota amended its HCB waiver program for people with developmental disabilities in order to cover "housing support coordination services". Minnesota pays up to \$500 per person to housing specialists who are dedicated to working with waiver participants in locating housing in the community. While case managers can perform the same function, Minnesota broke this support out into a separately offered HCB waiver service because case managers frequently do not have the time nor the expertise to effectively aid people in locating housing. This type of coverage can serve as a source of Medicaid funding to provide active assistance to individuals in locating a home and obtaining assistance from outside the DMR system.²²

The second additional change is more complex. Federal HCB waiver statutes prohibit Medicaid dollars from being used to pay for "room and board" costs. The expectation in the HCB waiver program is that participants will meet their housing and other living expenses out of their own resources (e.g., SSI, earnings, food stamps and so forth). In ICFs/MR, of course, federal payments are made for room and board (e.g., facility mortgage costs, utilities, and food). The different treatment between ICFs/MR and the HCB waiver program stems from the fact that ICF/MR residents only receive a nominal SSI payment.²³

In 1990, Congress enacted an exception to this prohibition. In particular, Congress provided in Section 1915(c)(1) that states are authorized to pay for the "room and board" expenses of "live-in caregivers". In July 1994, HCFA promulgated regulations concerning this change. In particular, HCFA affirmed that a state may obtain reimbursement for "a portion of the rent and food that may be reasonably attributed to the unrelated caregiver who resides in the same household with the waiver recipient" (42 CFR 441.310(a)(ii)). The regulation makes it clear that this reimbursement option is available only in the case

of individuals who live in their own homes (e.g., it may not be employed in group home or foster care situations). Earlier this year, HCFA revised the standardized application format for the HCB waiver program to include pre-print language that enables a state to readily select this option.

When a state elects this coverage, it is able to employ Medicaid dollars to meet a portion of the costs (either rental or mortgage) of the waiver participant's living arrangement whenever it is necessary for a caregiver to live with the participant. This option is presently employed in the Missouri and Oregon HCB waiver programs for people with developmental disabilities. New Hampshire and Vermont recently modified their HCB waiver to include this option. In the case of Oregon, the live-in caregiver payment is approximately \$360/month. New Hampshire expects to provide up to \$500/month. To date, these dollars have principally been used to help offset rental costs, although the State is seriously looking at opportunities to assist people in meeting mortgage obligations.²⁴

In its HCB waiver renewal application, Connecticut elected not to employ this option. This decision should be reconsidered. The option gives a state a useful tool to access federal Medicaid dollars in support of individuals acquiring a home of their own. This is particularly important in Connecticut, where housing costs are high. As key stakeholders in Connecticut examine the supported living program, consideration of this option should be on the agenda.

Connecticut should assess the pending changes in federal Medicaid policy for their potential implications for how the State deploys federal dollars to purchase services and supports for people with mental retardation.

If Congressional proposals concerning Medicaid restructuring are enacted into law in more or less their present form, Connecticut will have enormous flexibility to restructure how it deploys Medicaid financing in its mental retardation service system. For example, eligibility for home and community-based services could be decoupled from eligibility for institutional services. Co-funding strategies that tie together federal, state, individual and family resources could be considered that are difficult to pursue under present policy. Voucher and direct cash assistance programs also become distinct possibilities.

Obviously, the reaction to federal policy change cannot and should not be the complete dismantling of the State's present system. Federal policy change, however, will permit each state to take a fresh look at its system of services and supports and the full range of policies that undergird it unencumbered by the present complications of Medicaid policy. Among the changes that all states will be able to consider are:

- Replacing the “need for active treatment”²⁵ as the principal determinate of eligibility for federally-assisted services with alternative criteria that are based on a more holistic assessment of an individual's need for community living supports that are not principally clinically-oriented²⁶;
- Funding mechanisms that wrap around a wide range of supports rather than being tied directly to the delivery of rigidly defined service categories and settings;
- Replacing case management models with personal agent approaches that are assistive/facilitative rather than “gatekeeping” in nature;
- Adopting more seamless, transparent approaches to eligibility, support strategy development, and payments policies; and,
- Giving consumers a greater role in the direct management of services and resources.

For example, about eighteen months ago, Rhode Island submitted a Section 1115 demonstration waiver request to HCFA that was designed to put consumers and families in the driver's seat in the development of support strategies, with a clear emphasis on promoting greater choices and community inclusion. As the proposed federal Medicaid policy changes stand today, Rhode Island (and any other state interested in adopting a similar approach) would not require a waiver in order to proceed.

Acknowledging that the flexibility that would be granted to the states comes at a price (namely, the capping of federal payments), this flexibility also will mean that Connecticut will have a relatively free hand to restructure its services and supports for people with mental retardation, including concentrating its attention on strengthening and expanding its supported living program. This poses a major opportunity for Connecticut to embrace supported living as its central strategy in enabling people with mental retardation in securing tenure. More broadly, the federal policy change also means new opportunities for states to unify the management and operation of their systems under a single set of principals and goals.²⁷ Finally, there will be improved opportunities to meld together supported living and personal assistance models to yield a more coherent, transdisability approach to supporting people who live on their own.

E. STRATEGIES RELATED TO PERSONAL ASSISTANCE

Clearly, advocates for personal assistance services achieved a major breakthrough in securing the go-ahead to submit an HCB waiver program request in order to secure Medicaid financing for these services. This request potentially paves the way for putting into place a long needed, more robust extension of current state-funded personal assistance programs. This is a long overdue step.

Absent changes in federal policy, securing the approval of and implementing this program ought to proceed apace. It can serve as the launching pad for the future expansion of personal assistance opportunities in Connecticut. The process that has been employed in the development of the proposed program clearly aided in finding common ground concerning some of the essential aims and principles of personal assistance. The HCB waiver initiative is a good start.

At the same time, the waiver initiative obviously is in danger of running headlong into the federal policies changes outlined above and potentially is endangered as a result of the proposed caps on federal assistance to Connecticut. For various reasons, Connecticut is a state that would not fare particularly well under the formulas that have emerged in either the House or the Senate.

In spite of the uncertainty that attends federal policy, it remains the case that the essential purpose of the waiver initiative — to broaden and enrich the availability of personal assistance services — is still valid. Launching this program makes sense from the standpoint that, from an overall policy perspective, Connecticut should step up its supports for individuals with disabilities so that they are able to live independently in their communities. It also makes sense because the availability of personal assistance services will prove to be a key ingredient in Connecticut's repositioning its Medicaid program to live within the proposed federal assistance caps. There is clear evidence that personal assistance services are more economical than nursing facility or home health services in meeting individual needs for supports.

In this vein, studies by the World Institute on Disabilities and other organizations also have demonstrated that consumer-directed personal assistance services (i.e., organized along the lines of

Connecticut's present Personal Care Assistance Program) husband scarce resources to the best advantage of consumers. Under present federal Medicaid policies²⁸, the HCB waiver proposal has had to be structured employing a "broker agency" model rather than a direct consumer assistance model. Under the changes in federal policy that have been proposed, Connecticut will have the latitude to employ both models and, thereby, give individuals the choice of which they would prefer.

From a broader perspective, the proposed policy changes also would open up the possibility of Connecticut's redirecting dollars spent on home health services for people with disabilities to personal assistance. In particular, individuals eligible to receive home health services could be offered the option of receiving personal assistance services instead, an alternative that is not feasible under present federal policy due to the narrow categorical nature of home health services. To the extent that substituting personal assistance for home health proved to be more cost effective, then the resulting savings could be reinvested in expanding the availability of personal assistance services to other individuals. The federal policy changes also would clear the way for states to more readily offer personal assistance and other supports in lieu of nursing facility services for people with disabilities. Many of the perceived federal policy obstacles to states helping people avoid institutionalization would disappear.

People with disabilities in Connecticut rightly regard the availability of personal assistance services they can control and direct as the linchpin in their being able to live independently in the community. Historically, federal and state Medicaid policies have led to an overemphasis on medical and institutional models. Via the proposed HCB waiver program, the first steps can be taken to establish personal assistance services as a substitute for those models. Over the long haul — and, particularly in light of the pending federal Medicaid changes — the agenda in Connecticut must be to press forward with the expansion of personal assistance as a more cost-effective and efficacious way to support people with disabilities in their communities. Expanding personal assistance will result in limited federal dollars being employed as productively as possible. Again, we point out that flexibility that would be afforded by the federal policy changes also lends itself to Connecticut's being able to take a serious look at melding together supported living and personal assistance into a more seamless approach to supporting the needs of people with disabilities.

F. SUMMARY

Connecticut is a state that has started down the road of transitioning its public support systems from reliance on facilities and medical models to emphasizing "partnership/membership" models. The policy changes needed in Connecticut to support people with disabilities securing tenure lie along the pathway of expanding supported living and personal assistance. Each is a linchpin in bringing needed supports to individuals so that they may freely select where and with whom to live.

Most clearly, the pending changes in federal Medicaid policy pose challenges to states due to the prospect for reduced future federal assistance. At the same time, they also offer enormous potential for states to restructure their existing programs so that they resolutely focus on the delivery of person-centered supports.

IV. INCOME POLICIES

“What sources of income assistance are available to people who live on their own?”

There are many changes in public policy that can be made so that a state can offer services and supports to people in their own homes. That is a very important part of the equation in enabling people to live where and with whom they want.

Having a home of your own poses financial obligations. People with low incomes have serious problems meeting those obligations. This can be especially true for people with disabilities, many of whom rely on SSI payments, have diminished earnings capacity or are not able to find work.

Various state policies can affect the income of people with disabilities. For example, in some instances, states have adopted policies that effectively impose a very high tax rate on the money people earn by cutting back public assistance payments on a dollar-for-dollar basis for each dollar earned. Other policies similarly can result in individuals having to contribute all the dollars they make to meeting the “cost of care” and, hence, not having money available to acquire a home of their own or meet living expenses. Still other policies can make it difficult for individuals to save up the money they need to purchase a home or set up housekeeping.

Here, we look at Connecticut’s policies that affect the incomes of people with disabilities.

A. CONNECTICUT’S POLICIES

For adults with severe disabilities, the federal SSI program guarantees a basic income floor. States may elect to supplement such SSI payments. Many states do not. Connecticut wisely has decided to make such supplement payments. Indeed, compared to most other states, Connecticut is less parsimonious in its SSI supplementation (a maximum of roughly \$300/month). Connecticut’s supplementation policy has the added benefit of allowing more people with disabilities to qualify for Medicaid funded services. While Connecticut is to be applauded for supplementing (particularly in light of the fact that most other states do not or provide even smaller supplements²⁹), it needs to be kept in mind that the supplement still leaves people with disabilities who have no other income with only roughly two-thirds of the dollars that, under federal housing guidelines, lead to classifying a household as very low income in Connecticut.

Connecticut’s supplement is based on providing SSI-recipients with a housing allowance that is tied to market rents. The chief shortcoming of this allowance is that it is based on low-end market rents even though there is a documented scarcity of acceptable housing available in many areas of Connecticut at the standard used to determine the supplement. This problem has been recognized by the Department of Social Services. A higher level of supplementation is needed if people with disabilities are to be able to access modest but still acceptable housing.

Connecticut also offers a variety of “special needs” supplements, including security deposits for housing and heating. Some of these other special needs supplements can provide modest assistance to people with disabilities who want a home of their own, particularly in helping meet the costs of setting up a household.

Connecticut also makes special supplement payments when a person is served in a “boarding home”. These payments are vendor payments and do not constitute income assistance per se. The amount of these payments is determined by the state. As with DMR room and board payments, these dollars subsidize facility-based operations. People who leave such settings revert to the State’s basic supplement program. In some states, there is a wide difference between the amount of these facility-based supplements and individual supplements for people who live on their own (which can create a barrier to people leaving such facilities). Connecticut’s policies are more even handed.

In most public assistance programs, individuals who obtain employment will see their public assistance grant reduced by some percentage of the dollars they earn.³⁰ Generally, Connecticut’s policies with regard to the treatment of earned income mirror federal policies. Connecticut disregards a portion of earned income and reduces payments for one-half the remainder. As a practical matter, Connecticut’s policies are no more restrictive than federal policies. Similarly, Connecticut’s asset eligibility tests are slightly more restrictive than federal policy.³¹ If an individual owns a home, the value of the home is exempted when eligibility for benefits is determined.³²

A state’s income assistance policies, particularly in the case of adults with disabilities, are intertwined with Medicaid eligibility policies. Eligibility for public assistance is tied into Medicaid eligibility. Medicaid eligibility is important for people with disabilities simply because it enables them to obtain health care. Most states extend Medicaid eligibility automatically to individuals who qualify for SSI. Other states do not. Connecticut does not automatically extend Medicaid eligibility to people with disabilities who receive SSI.³³ As a practical matter, the distinctions between Connecticut’s criteria for Medicaid eligibility and SSI-criteria are not significant. However, if Connecticut were to automatically extend Medicaid eligibility to all SSI recipients with disabilities, individuals would be able to more readily access Medicaid services.³⁴ Connecticut operates a “medically needy program” for individuals who are aged, blind or disabled.³⁵

Connecticut’s most generous policy with regard to Medicaid eligibility is in the area of institutional services. There Connecticut has elected to extend Medicaid eligibility to individuals whose incomes are as high as three times the federal SSI standard (roughly \$1,380 per month). This means that people considered for admission to ICFs/MR and nursing facilities can have higher incomes than individuals in the community. This allows more people to qualify for institutional care. At the same time, such individuals are expected to turn over all their income in excess of a small personal needs amount in order to offset the cost of care.

Because HCB waiver services serve as an alternative to institutionalization, Connecticut has elected to apply the same income tests to these services as it does ICFs/MR and nursing facilities. The effect of this policy is to “level the playing field” in terms of financial eligibility for institutional and community services. People can remain in the community and still have access to Medicaid funded services, including those available through the regular Medicaid program.

As opposed to institutional services, however, Connecticut has elected to not require that HCB waiver recipients contribute all their “excess income” to offset the cost of services. This means that individuals are able to retain a significant portion of their earned income in order to meet their daily living and housing expenses.³⁶ In this respect, Connecticut’s policies are nearly as generous as federal law permits.

Federal SSI policy changes are being considered by the Congress in conjunction with “welfare reform”. Generally speaking, most of the changes under consideration would affect the eligibility of children with disabilities to receive SSI cash payments. Changes in SSI policies under consideration for adult recipients generally speaking would not affect individuals with significant cognitive impairments or other severe disabilities.

B. OBSERVATIONS

Among the states, Connecticut’s policies regarding SSI supplementation, the treatment of income and linkages to Medicaid eligibility are more generous than most. New Hampshire’s individual supplement, for instance, is pegged at only provides a \$13/month.

Some (but not many) other states (most notably California) have more generous policies. California and Oregon, for example, provide special supplements to aid people in purchasing in-home supports. Connecticut’s policies concerning supplements for board and care homes are not unusual.

The most widely recognized problem in Connecticut’s supplementation policies lies in their adequacy for ensuring that SSI recipients are able to rent acceptable housing. While there are all sorts of options available for a state to access Medicaid dollars to pay for services and supports, there are only limited avenues in Medicaid to help people meet their housing costs outside facility-based settings. Moreover, Medicaid is an administratively costly program to operate and, hence, paying for services and supports is more complicated than simply seeing to it that people with disabilities have their own resources. In many regards, cash assistance rather than “program assistance” would serve many individuals far better than Medicaid financing. The inadequacies of the existing supplement prompted DMR to establish its housing subsidy program (which is discussed in the next section). Supplementation also can serve as a vehicle for assisting individuals to purchase their own supports. For example, Colorado provides a special “home care” allowance of \$300 to people with disabilities. For many people, that allowance is exactly what they need in order to avoid dependency on formal service structures and meet their needs in a self-directed fashion.

At the same time, there is little doubt that reformulating income assistance policies means that, at least in the short run, a state must be willing to step up its outlays. The benefits of more generous policies are long rather than short-term. Still, it would be of benefit to Connecticut to review some of the steps other states have taken to revamp their income assistance programs to furnish additional assistance to individuals to live independently in their communities.

Failing change in income assistance policies, probably the most important observation that can be made about Connecticut’s policies is to keep in mind that their net effect in the best of all circumstances is to leave most people with disabilities in poverty (e.g., with incomes well below the benchmark for an individual’s being classified as “very low income”). This means that other housing subsidy options (some of which are discussed in the next section) may need to be used in order to assist a person to have a home of their own. It also means that it continues to be very important for Connecticut to stress employment programs for people with disabilities.

V. HOUSING POLICIES & ACCESS

*“What options are available to make housing more affordable?”
“How are people connected to supports and other assistance to help them
have a home of their own?”*

Over the past several decades, the federal government and the states have created a frequently confusing array of programs with one end in mind: assisting low-income people in obtaining housing. These programs subsidize individuals (in the form of aiding them to acquire housing at “below market” costs) or organizations (by providing them with other sorts of subsidies in order to permit them to build more affordable housing). One aim of the Home of Your Own initiative aims at linking people with disabilities into these various programs to increase their opportunities to choose where they will live.

In Connecticut, state, local, and non-profit agencies sponsor and participate in these programs. In many cases, community agencies serving people with disabilities have been able to employ these programs to construct facilities. Until the advent of the Connecticut Home of Your Own Project, however, there has been no focused examination of how all these various programs and options could be employed specifically to help people with disabilities find their own housing.

It is not our aim here to duplicate the work that already has taken place and will occur in terms of creatively linking people with disabilities in Connecticut to both public and private home ownership resources. We offer comments about the general tenor of housing policy in Connecticut and offer some suggestions concerning other steps that the state might take to aid in making housing more affordable and how people might be assisted in better accessing affordable housing.

Here we also discuss related issues concerning providing assistance to people in locating affordable housing.

A. HOUSING POLICY IN CONNECTICUT

Connecticut is noteworthy for having gone beyond the confines of simply administering federal housing programs to creating its own set of programs to complement and fill the gaps in the federal programs. For example, the State operates a down payment assistance program to help low income households acquire a home of their own. The state also offers below market rate loans and outright grants to non-profit developers of affordable rental housing as well as innovative models including mutual housing, limited equity co-ops, and housing on land trusts. Connecticut has a particularly vigorous record of embracing particularly creative strategies for increasing the supply of affordable housing. There are several noteworthy examples of cooperative housing in Connecticut that have enabled people with disabilities to secure an affordable place to live. Strategies such as these will take on even greater importance, given the likelihood that federal housing dollars will be sharply reduced.

Connecticut’s disability activists have been successful in making state housing programs more responsive to the needs of people with disabilities by guaranteeing that 10 percent of all state-supported housing units be accessible and that those units be similarly configured as other units in the complex. Connecticut’s Building Code also has been amended to conform to the federal Fair Housing Amendments Act of 1988. Still, people with disabilities continue to report problems in locating wheel-

chair accessible housing. The supply of state-supported housing is limited. In order to increase the supply of accessible units, more will need to be secured through the private sector. A three-pronged strategy can be considered, including: (a) working with the Attorney General's Office to develop an enforcement strategy; (b) working with landlord associations to enlist their support in improving compliance; and, (c) direct financing of home modifications through HCB waiver programs.³⁷

Connecticut's willingness to strike out on its own is particularly important in a state that saw the costs of housing rise very rapidly during the 1980s. Even though housing costs have leveled off in recent years, owning an even modest home remains out of the reach of many households absent special assistance.

Connecticut has not solved the housing affordability problem. The *1995 Consolidated Plan for Housing and Community Development* clearly spells out the wide range of issues that confront the state. The plan is particularly well-crafted in terms of its treatment of housing needs for special needs populations (including people with disabilities). Moreover, we note that the Department of Social Services has launched its own working group to look at its policies and practices to see where they can be changed to help individuals obtain affordable housing.

Very clearly state and federal budget concerns will affect Connecticut's efforts in this arena. There is every prospect that the federal deficit reduction agenda will further undercut federal assistance in the area of housing for low income individuals. It is uncertain to what extent Connecticut itself will sustain its current programs. We hope that it would be able to.

Congressional proposals affecting federal housing programs are likely to feature two major changes. First, the federal dollars available for housing will decline sharply. Second, the central thrust of those proposals is to redirect these reduced dollars from "project-based assistance" to "tenant-based assistance". Other changes are intended to make housing vouchers/assistance programs more attractive to private-sector housing suppliers. These changes, obviously, will have major consequences for all low income households. Once Congress completes action on these changes, it will be important that the Connecticut HOYO project obtain updated information concerning the effects of these changes. In addition, significant cutbacks in federal housing dollars will place an even greater premium on building bridges to public and private housing finance authorities.

For the purposes of this policy review, Connecticut's current housing policies and programs offer numerous opportunities to assist people with disabilities in having a home of their own. Work is well underway in building the connections that are needed so that people with disabilities may be better able to access what, relative to many other states, is a rich array of well-established programs to aid low income individuals obtain affordable housing.

B. POLICY STEPS

Making better use of generic public and private housing resources is a central objective of the HOYO project. Beyond this central objective, the question can be asked: "What steps can Connecticut take to make it more possible for individuals with disabilities to overcome the financial barriers they face in obtaining a home of their own?"

People with disabilities do not need special housing but they may need at least limited aid in overcoming the financial barriers to obtaining housing. For example, in most states there is a long waiting time to

obtain a HUD Section 8 voucher. This waiting period can trap people in facilities. With a voucher, they might be able to locate affordable housing. However, if their moving is contingent on having a voucher in hand, they may never be able to move. In instances like this, some form of interim and frequently modest financial assistance would see them through.

There are steps that Connecticut can pursue that would aid in making housing more affordable and accessible for people with disabilities. We have already mentioned the “live-in caregiver” option that can be added to the State’s home and community-based waiver program. That option enables accessing federal Medicaid dollars to pay for either mortgage or rental costs.

The Department of Mental Retardation already has taken another important step. DMR operates a “housing subsidy” program in tandem with its supported living program that makes up the difference between the income available to supported living participants and their living expenses. Such subsidies are presently furnished to about 500 individuals. Only a few other states have been willing to take this step (Florida, for example, has a housing subsidy for its supported living participants). The DMR housing subsidy is crafted to ensure that other sources of assistance are tapped first prior to a subsidy’s being authorized. While the funding for such subsidies is limited, the program does represent an enormously positive step on DMR’s part to create enhanced opportunities for people to have a home of their own. We point out that adopting the “live-in caregiver option” in the DMR HCB waiver program would provide an opportunity to stretch available subsidies further by accessing additional federal Medicaid dollars.

It is important to recognize that this subsidy program merely has the effect of creating a more level playing field between facility-based residential services and assisting people in having a home of their own. The housing costs associated with facility-based programs are heavily subsidized through federal Medicaid payments (in the ICF/MR program) and state general fund dollars in the case of other CLAs (via “board and care” SSI supplementation payments). Indeed, DMR operates a special \$4 million revolving loan fund to assist in the development of facility-based services. What distinguishes the supplement from the subsidies that flow to facilities is that the former is overt while the latter is a “cost of services”.

A potential defect of the housing subsidy program is that it is geared only to meeting rental costs and not ownership costs. Serious consideration should be given to treating either type of cost equally, regulating the amount of the subsidy against the fair rental benchmark. Obviously, helping a person purchase a home means that the subsidy also is aiding the individual build equity and, therefore raises the question of whether the state should make the payment of the subsidy contingent on an individual’s agreeing to a secondary lien on the property that permits the state to recover its subsidy if the person should dispose of the property. We do not believe that such lien arrangements are appropriate. Such liens are not employed in other housing assistance programs. Furthermore, since the subsidy would continue to be regulated by fair market rental standards, allowing the subsidy to assist an individual in purchasing a home would have no net effect on costs to the State.

For the future, DMR should develop (and gain executive/legislative approval) for a funding mechanism that will transfer whatever portion of facility-based payments that are earmarked for housing into the housing subsidy program as those programs are converted to supported living. In addition, DMR should make obtaining additional funding for the subsidy program a central priority in future budget requests.

There is no similar housing subsidy program available to individuals who do not qualify for DMR services. The DMR program is designed to fill in the gap between the assistance available from income assistance programs and actual housing costs. Serious consideration should be given to broadening the availability of housing subsidies to other populations as well. This can occur via revamping Connecticut's SSI supplementation policies or through more targeted, limited appropriations. Aiding individuals in obtaining affordable housing cuts across disability lines.

A small number of states have elected to earmark dollars to help people make down payments and cover closing costs so that they may purchase a home. For example, both Rhode Island and Michigan have collaborated with their State's housing finance authority to combine limited state dollars with low cost financing to enable people with disabilities to purchase their own homes. Individuals bring whatever money they can to the table and the State makes up the difference. In each case, a relatively small amount of state money (roughly \$5,000 in Michigan, for example) puts individuals in the position to buy their own home. These initiatives are creative partnerships that bring the person, the public and the private sectors together in support of people having a home of their own. This step also should be considered in Connecticut to the extent that generic housing programs cannot fulfill this need.

Another development of interest in aiding people with disabilities to secure housing lies in enlisting parents to assist in co-funding home purchases. For example, Fannie Mae has revamped its mortgage underwriting rules to permit family members to assist individuals in making downpayments. State housing authorities are beginning to follow suit. For example, New Jersey's Housing Finance Authority has adopted underwriting rules that mirror those of Fannie Mae. New Jersey also has earmarked a portion of the proceeds of a \$160 million bond issue³⁸ approved by state voters last November to support home ownership, including co-funding home ownership with families/family consortia. Not all families are able to participate in co-funding home ownership. Still, those who are able can be important partners in helping individuals secure a home.

Finally, we simply point out that, as a practical matter, one of the most common tools in making housing more affordable for people with disabilities is to encourage roommate and other types of shared living arrangements. At the same time, this is not a universal solution to making housing more affordable. It is enormously important to respect individual choices and preferences in this regard. However, it should be a topic that is covered in any person-centered planning process (by asking the fundamental question of "where and with whom would you like to live?"). Frequently, working out roommate arrangements poses the most practical opportunity for people to overcome the financial hurdles to having a home of their own.

C. HELPING PEOPLE FIND HOUSING

Helping people find housing and navigate housing assistance programs is another important topic. Service systems remain largely organized around facility/program-based models. Under those structures, the task of locating housing involves finding which facility or program has a vacancy and determining whether the person "fits" the program. In the "supports paradigm", housing is separated from services. Special attention needs to be paid to helping (as necessary) people to locate a home of their own.

Many people with disabilities are entirely capable of locating and arranging for their own housing. Often times, family and friends also can be enlisted to help the person. There is certainly no need for a state to dictate that individuals must use or rely on some third-party in arranging for housing. At the

same time, some individuals would benefit from having assistance available to help them locate their home and obtain whatever assistance is available to make it more affordable. Service systems that seek to support people where and with whom they choose need to develop the capacity to furnish this type of assistance.

This capacity is multi-faceted. In particular:

- Individuals and the people who support them need access to current, reliable up-to-date information regarding the types of assistance that they can tap in order to secure housing.
- Second, since housing markets are local, having information amount what is available in the person's community is important.
- Third, if the person needs and wants assistance in locating housing, he or she should have access to some one who will spend the time necessary. In other words, people should have access to agents.

Enabling people to find the best housing that will meet their needs and budget requires that they have good information and, if desired, some one to help them explore the market place. The Connecticut HOYO project is addressing the first two topics.³⁹ These are important basic steps to take.

In the final area, it is perhaps helpful to point out that there are several options for making an agent available to assist the individual in connecting to housing and housing assistance programs. These are:

- **Service/Support Coordination System.** Helping individuals locate housing and access housing assistance programs can be made a responsibility of service/support coordinators (case managers). Generally, people have such a coordinator. With the advent of the "support paradigm", the role of such coordinators is shifting from traditional case management models to community facilitator/personal agent models. At the same time, coordinators typically are assigned many different tasks and, therefore, frequently lack the time needed to assist people who need active help in finding housing.
- **Supported Living Agency.** In many instances, performing this agent role is the responsibility of the agency who arranges for or provides various supports to the individual. In Florida, for example, "supported living coaches" are expected to help people locate housing and make necessary arrangements.
- **Housing Coordination as a Separate Service.** Finally, housing coordination and assistance can be defined as a distinct function. As mentioned earlier, Minnesota has added the coverage of housing coordination to its HCB waiver program. The state did so for two reasons: (a) case managers carry very heavy workloads and, consequently, cannot readily serve as "agents"; and, (b) the State wanted the latitude to contract with individuals and agencies which are specifically expert in housing and housing assistance.

We point out these options but do not recommend a specific course for Connecticut to follow. Each option can work equally well, depending on circumstances. What is critical is less which option is

selected than that people have reliable access to someone who can serve as an agent on their behalf. However this function is performed, it can be qualified for federal Medicaid participation (under targeted case management, as a service cost, or as a stand-alone HCB waiver service). At least in some of the more populous areas of the state, the Minnesota approach might prove useful as a means to forge a partnership with local housing authorities.

We note that the DMR Waiting List Task Force identified the “personal agent” concept as one of the critical steps that Connecticut could take in realigning its service system to build upon natural and community supports. That concept should be pursued. As conventionally defined, “case management” systems are usually ill-equipped to furnish the types of assistance that many people require. In Florida’s supported living program, the supported living coach has an agent role. More broadly, the State’s independent support coordination system offers an exemplary model for making available a much more personalized approach to person-centered services.

D. SUMMARY

Connecticut has crafted several strategies independent of federal housing programs to make housing more affordable to its low-income citizens. Through the HOYO project, people with disabilities are being connected to those resources. DMR’s housing subsidy program is another good example of how a state can aid people with disabilities to be able to afford housing. Certainly, that program is an important cog in Connecticut’s shifting from a principally facility-based system of residential services for people with mental retardation to broadening opportunities for supported living for people with mental retardation. The State should take the next step in making such subsidies generally available to people with disabilities. In addition, in light of the proposed reductions in funding for federal low income housing programs, state and private housing finance options will become increasingly important.

In the arena of assisting people to access housing and housing assistance programs, fostering an “agent” approach will prove to be a critical step to which Connecticut needs to give serious consideration. For many people with disabilities, having the support of such an agent will prove enormously important in their being able to take more command over their lives.

BACKNOTES

1 Robert Prouty and K. Charlie Lakin (eds.) (June 1995). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1994*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

2 Connecticut Home of Your Own Initiative, Draft Mission and Plan (6/19/95).

3 Robert W. Prouty, and K. Charlie Lakin (eds.) (June 1995). *Residential Services for Persons with Mental Retardation and Related Conditions: Status and Trends Through 1994*. Minneapolis: University of Minnesota, Research and Training Center on Residential Services and Community Living.

4 Ibid.

5 According to DMR, there were 1,270 individuals on the waiting list in November 1994, including 381 classified as on emergency or "Priority 1" status. Between 1991 and 1994, the number of individuals on the waiting list grew by about 50%.

6 Kathy Ludlum's comments were especially helpful in developing the description of these programs in this section.

7 Home health services must be delivered by certified home health agencies. Achieving certification is a costly process. Home health rules require that home health aides be supervised by nurses, which adds another layer of expense. Under current federal law, all states must cover home health services. In states which do not offer personal care services under their state Medicaid plan or which do not operate an HCB waiver program which offers personal care/assistance, by default home health is frequently the only available source of in-home services. Home health services are "medical" rather than supportive in nature and, hence, are controlled by home health plans developed by the home health agency. High utilization of home health services frequently is the result of the absence of cost-effective substitutes. Even when a state offers such substitutes, some of the same problems encountered in the home health coverage also pop up. Some states, for example, limit the provision of personal care services to home health agencies.

8 The program is intended for adults with disabilities (physical and/or mental), ages 18-64 who meet state income and asset tests and who would "require institutional placement if not provided with significant supportive services". Services offered include: case work, companion, chore, homemaker, and personal emergency response systems. The program "is not an entitlement program". The purchase of services on behalf of individuals is capped at no more than \$650.00 per month. Participants can manage services directly, including hiring, firing and paying support workers. Elderly individuals were previously eligible for this program. They have since been shifted to the State's Home Care Program for Elders.

9 PSP operates under relatively generous income guidelines (up to 300% of the Supplemental Security Income benefit for an individual). Personal assistance can be furnished to assist an individual in both ADLs and IADLs. Individuals or a surrogate must supervise the attendant. Consumers manage the hiring and attendant payment process. Since funds are limited, a random selection process is employed to enroll individuals to participate in the program as funding allows.

10 See *There's No Place Like Home*, The Annual Report on the Connecticut Home Care Program for Elders (Department of Social Services, 1994).

11 A state may at its option offer personal care services to Medicaid recipients. About 30 states offer such services under their Medicaid state plans. Unlike a home and community-based waiver program, a state cannot limit personal care services furnished under a state plan to specific groups of individuals with disabilities nor can it limit the total number of persons who receive such services. In the Omnibus Budget Reconciliation Act of 1993, Congress enacted new provisions concerning the coverage of personal care under a Medicaid state plan. The new provisions: (a) give a state more flexibility in determining the need for personal care services; (b) remove the requirement that such services be supervised by a nurse; and, (c) permit such services to be furnished outside the person's home. The new provisions clear the way for states to offer personal care services along less medically-oriented lines than in the past.

12 Please see: Department of Social Services: Medicaid Personal Care Services — Final Report (May 1995).

13 Nearly all other states make HCB waiver services available to people with disabilities other than mental retardation. Frequently, these services are offered to a target population composed of individuals who are elderly or disabled who would otherwise qualify for nursing facility care. Some states, however, have elected to establish distinctive HCB waiver programs for non-elderly individuals with disabilities. Illinois, for example, has had such a program in operation for several years. Maine also operates such a program.

14 Currently, about 13 states have secured HCFA's approval to offer HCB waiver services to individuals with an acquired brain disorder. These include New York, New Hampshire, and Vermont.

15 "Comprehensive" service models are those which attempt to meet each person's needs solely through the use of publicly-funded services. The ICF/MR program is an example of such a model. An ICF/MR combines housing (in the form of a facility), "round the clock" staffing, and "active treatment" within a single program. The ICF/MR operator is held responsible for delivering all services that a resident is deemed to require. The "partnership/membership" model is based on meeting an individual's needs by blending together public, natural and community supports. It recognizes that overreliance on paid supports results in greater dependency and works against community inclusion. The model does not ignore individual needs; it simply stresses that such needs be met by enlisting other sources of support rather than relying exclusively on paid supports.

16 Between 1990 and 1995, federal Medicaid spending for ICF/MR and HCB waiver services for persons with developmental disabilities grew at approximately 9% a year. The total number of individuals receiving both types of services grew at a somewhat faster pace because states focused on the development of lower cost HCB waiver options. The Congressional Budget Resolution calls for the overall rate of growth in Medicaid spending to be ratcheted down to 4% a year by 1998. Absent major shifts in the composition of state service systems, the prospects for these systems being able to address accommodate present and future demand for services will be sharply curtailed.

17 We also note that, in the CSLA program, each of the eight states convened a steering committee to aid it in crafting its program. These steering committees remain active today. In each instance, these committees (most of which have considerable consumer representation) have contributed enormously to the success of these programs.

18 With regard to supervision, Connecticut's program is defined in a similar fashion to a program operated in Michigan which limited eligibility for "independent living" services to individuals who require supervision of 23 hours or less. The same problem emerged in Michigan when some agencies pushed this boundary in order to support people with more intensive needs in homes of their own.

19 They are contained in A Guide to Supported Living in Florida (Supported Living Project, Florida Department of Health and Rehabilitative Services).

20 "The department's ability to creatively use the money already in the residential system is very limited. The department is capped each year not only by the total amount of funding for residential services, but also by actual numbers of individuals that can be served. Even if more individuals could be served for the same amount of money it is not allowed due to funding restrictions." Waiting List Planning Committee, Planning Report to Eliminate the DMR Waiting Lists.

21 In particular, DMR may now furnish residential habilitation services to individuals who live on their own. The complete list of services offered under the DMR waiver includes: (a) residential habilitation; (b) day habilitation; (c) prevocational services; (d) supported employment; (e) respite care; (f) family training; and, (g) environmental modifications (home adaptations).

22 More information concerning this coverage can be obtained by directly contacting Minnesota's HCB waiver coordinator.

23 While there is a certain "logic" to this differential treatment, typically ICF/MR costs for room and board expenses run well above the amounts HCB waiver participants have available to meet their living expenses. Consequently, there is an implicit room and board subsidy in payments to ICFs/MR.

24 The mechanics of this option are relatively straightforward. The "live-in caregiver" payment is made to the caregiver but the caregiver must have entered into an agreement with the waiver participant to turn these dollars over to the individual (the agreement documents the cost). The costs that may be covered vary from state-to-state. Oregon fixed the costs at the federal SSI standard for an individual who lives in a home of another. Elsewhere, states set a maximum payment limit and pay up to the limit or the live-in caregiver's share of apportioned expenses, whichever is less (if the caregiver and a single participant share the living arrangement, then costs are apportioned equally). The participant, in turn, uses the payment to meet a portion of his or her lease or mortgage payment. In New Hampshire, rulings have been obtained from the Social Security Administration that make it clear that such payments do not affect the individual's eligibility for SSI payments. The National Home of Your Alliance may be contacted for additional information regarding this option. HCB waiver coordinators in New Hampshire (Matthew Ertas) and Vermont (Theresa Wood) can be contacted for information regarding how those states are employing this option.

25 Under current federal law and policy, a person's eligibility for HCB waiver services is contingent on determining that the individual would otherwise be eligible for ICF/MR services. This requires an affirmative determination that the individual requires "active treatment" which is generally understood as a comprehensive and "continuous" program of training and related services. During the 1980s, HCFA's "unwritten" policy (portrayed as the "moral equivalent" of active treatment) was that waiver participants receive an equivalent set of services through the HCB waiver program in order to validate their eligibility. During the 1990s, this "unwritten" policy faded. While individuals still must be determined as being otherwise eligible for ICF/MR services, HCFA does not regard that determination as dictating that recipients receive an equivalent set of services via the ICF/MR program. Instead, the individual's plan of care is simply expected to reflect his or her need for various service and supports that are offered under a state's waiver program. There has been a similar evolution of HCFA policies concerning 24-hour supervision. During the first few years the HCB waiver program was in operation, HCFA disapproved some state proposals to cover "semin-independent" living services because they did not provide 24-hour supervision. As a consequence, some states limited their coverage of residential services to group homes or family foster care situations. This "unwritten" requirement also has disappeared. Still, in several states, these policies continue to be embodied in HCB waiver programs. For example, it was not until last year that New Hampshire changed its HCB waiver program to cover "intermittent support" services even though several states had directly incorporated supported living services in their programs for several years. Connecticut's HCB waiver program is replete with references to "active treatment". Whatever unwritten policies that may have held sway in the past (or presently), Congressional proposals to restructure the Medicaid program clearly provide that a state may offer "home and community-based services" as well as "community supported living arrangements" services but do not contain provisions that require a state to condition the eligibility for such services on a person's need for institutional services (and, in the case of people with developmental disabilities, by inference, the need for active treatment or 24-hour supervision furnished in an ICF/MR).

26 For example, a state could offer home and community-based services to an individual whose sole need is personal assistance without having to accompany such services with a training program.

27 It is worth pointing out that one of the important factors that motivated Rhode Island to seek a Section 1115 demonstration waiver was in fact to unify its service system through single stream funding (by extinguishing categorical funding) and a common approach to support strategy development that emphasized consumer/family involvement. Under the proposed federal policy changes, the State may simply proceed to implement its program because the federal statutory and regulatory restrictions that necessitated the submission of a waiver request would no longer apply.

28 Under present federal policies, states are barred from making direct cash payments to recipients. These policies dictate that the state Medicaid agency make payments to the vendor/provider of services. As a result of this prohibition, states have had to resort to other devices in order to enhance the ability of individuals to exercise control over the delivery of personal assistance services. One such device is passing payments through a broker agency that serves as intermediary for the consumer. Another device is the use of two-party checks that the individual receiving personal assistance endorses only if the personal assistant has provided satisfactory services. Elsewhere states empower consumers by stressing their freedom of choice to select (and, if desired, change) any qualified provider. Free choice of providers is not waived in HCB waiver programs. Many people with disabilities, however, prefer to directly manage all aspects of the personal assistance services they receive. Several personal assistance programs that are financed with state-only dollars (e.g., which do not employ Medicaid financing) provide for direct consumer management of services. Supported living programs, of course, face the same issues.

29 Hawaii, for example, only provides a supplement of \$9 a month in a state with a very high cost of living.

30 Various Social Security “work incentive” programs (e.g., PASS and IRWE) can be used to help a person pay for work expenses (including training) and keep control over dollars that they otherwise might lose.

31 The State’s asset limit is \$1,600 versus \$2,000 under the SSI program.

32 This is known as the “homestead exemption”. However, individuals who own a home are subject to a lien. The lien can be exercised when the person dies in order to recoup the costs of Medicaid benefits that the individual may have received. This lien requirement is the result of federal statutory changes made in 1993.

33 Technically, Connecticut is classified as a “Section 209(b)” state. States in this category elected to maintain their own disability criteria for determining Medicaid eligibility when the SSI program was created in 1972. There are roughly a dozen such states. Connecticut may elect to drop this status whenever it chooses. In 1994, for example, North Carolina decided to take this step in favor of automatically extending Medicaid eligibility to all SSI recipients.

34 When SSI eligibility automatically triggers Medicaid eligibility, individuals only have to apply once for services.

35 Under a “medically needy” program, the medical expenses that low income individuals incur on their own behalf can be considered as reductions in their income. Such individuals are said to “spend down” in order to qualify for Medicaid. The “medically needy” option is most relevant in the case of individuals with disabilities who do not receive an SSI payment but have income over and above the state’s standard of assistance. Typically these are individuals who receive social security payments in excess of the grant standard.

36 In technical terms, Connecticut has established a “maintenance allowance” for HCB waiver participants. The amount of this allowance is disregarded for purposes of determining how much money an HCB waiver participant contributes toward the cost of the services and supports he or she receives. This provision affects principally individuals who do not receive SSI. SSI recipients are governed by the rules of the SSI program with regard to the treatment of earned and unearned income. A state may set this allowance as high as 300% of the individual SSI benefit. Connecticut’s present allowance is less than the federal ceiling but more generous than many other states.

37 In HCB waiver programs for people with developmental disabilities, “environmental modifications” are offered in approximately 80% of all the programs. Modifications (including ramps as well as bathroom and kitchen modifications) have long been recognized by HCFA as an allowable service offering. Modifications also are commonly offered in HCB waiver programs for elderly individuals who share with many people with disabilities similar needs for accessible housing.

38 One of the central purposes of this bond issue was to reduce the waiting list for developmental disabilities residential services. Rather than earmark all the proceeds of this bond issue to assist providers to purchase community residences, the State's master plan contains several initiatives designed to promote homeownership. Several of these initiatives will use bond funds to help leverage other dollars. New Jersey's strategy is spelled out in its Vision 2000 Master Plan.

39 As an aside, a new form of information sharing and networking has popped up in New Jersey. The Department of Human Services operates a computer-accessible electronic bulletin board system (named DHS On-Line). One area of this bulletin board is a "Mall" where individuals, families, and other interested parties can access on-line information and network about housing assistance programs. Realtors, for example, post to this area