

NATIONAL
HOME OF YOUR OWN
ALLIANCE

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

STATE POLICY REVIEW AND RECOMMENDATIONS

PREPARED ON BEHALF OF:

IDAHO HOME OF YOUR OWN INITIATIVE

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SUPPORTING IDAHO'S CITIZENS WITH DISABILITIES TO HAVE A HOME OF THEIR OWN:

STATE POLICY REVIEW AND RECOMMENDATIONS

1. INTRODUCTION

People with disabilities want a place to live that they can call their own. Their dreams are no different than 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 -- the ownership or lease of a home of their own. 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.

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.

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.

Idaho requested that the Alliance furnish technical assistance to improve the State’s capacity to help people with disabilities secure a home of their own. One component of the Alliance’s work with Idaho 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 Idaho 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 Boise in January to meet with State officials and a variety of other interested parties to discuss Idaho’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. This report offers observations, findings, and recommendations concerning Idaho’s policies in this arena

Idaho’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 Idaho’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 arena 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 Idaho’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 relate 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.
- *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 seen as 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 Idaho'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 Idaho's policies to answer the question: "*What assistance can people receive who live in a home of their own?*" We look at Idaho 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 Idaho'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 Idaho'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 IDAHO

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

In Idaho, as is typical in most other states, the answer is far less than they would receive if they were to be placed in a specialized living arrangement. In **many different** respects, the true nature of a state's policies concerning people with disabilities are discovered in how a state distributes its budgetary resources. Idaho spends a good deal of its resources on specialized living arrangements; it has been far less willing to spend these dollars to make services and supports available to people who live on their own.

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. This bias is being overcome through the rapid-paced expansion of home and community-based waiver programs as well as by 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 poised to make major changes in the Medicaid program. These changes can have enormous consequences for people with disabilities.

Idaho's programs for people with disabilities are in the early stages of the transition from relying almost exclusively on specialized living arrangements to offering more flexible supports that are better geared to supporting individual choice concerning where and with whom to live. More needs to be done, both within the developmental disabilities service system and in broadening the scope of supports that are available for people with other disabilities.

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

A. The Developmental Disabilities System

By far the largest and most distinct collection of “programs” that furnish/purchase services and supports for people with disabilities in Idaho are housed in the Idaho Department of Health and Welfare (DHW). DHW operates the State's single large public facility for persons with developmental disabilities (the Idaho State School and Hospital). DHW also purchases community residential services from the private sector. DHW also underwrites daytime services and other supports to people with developmental disabilities. DHW operates a regionalized contracting system through which it arranges or provides services to people with developmental disabilities and, recently, has launched a modest service coordination system.

The amount of money spent on behalf of people with developmental disabilities in Idaho is substantial. In 1992, Idaho spent \$57.1 million on specialized developmental disabilities services, more than double the amount in 1987² Overall, in 1992, Idaho ranked 25th among the states in terms of its total relative spending for developmental disabilities services but 18th in spending for community-based services³ Presently, about 5,000 persons receive services through DHW-funded developmental disabilities programs. Roughly one-third of these individuals receive some type of residential service.

The scope of Idaho's residential services for people with developmental disabilities is comparable to other states. In 1994, Idaho provided or purchased residential services of all types for 123.3 persons with developmental disabilities per 100,000 state population versus the nationwide average of 120.6.⁴ Measured in this fashion, Idaho ranked 26th among the states in the number of individuals receiving residential services relative to State population. In Idaho, people with developmental disabilities are less likely to receive residential services in small (6-bed or less) settings than is the case nationwide.⁵ Relative to its population, Idaho serves fewer people in its large public facility (ISSH) than is the case in other states.

When the types of living arrangements in which people live are broken down, one finds that the substantial **majority are congregate or facility-based living arrangements**. Roughly one person in eight is served at ISSH. About five out of eight individuals receive services in settings that house 7 individuals or more. Very few adults with developmental disabilities in Idaho today receive in-home services and supports. Nearly all live in a facility (ICF/ MR or a residential care facility⁶), a personal care home, or a foster care arrangement). *This distribution, of course, is opposite what one would expect to find in a system where most people are being supported in everyday living arrangements.*

In August, 1994, for example, fewer than 10% of all individuals who received some kind of residential service were "living independently" or in "semi-independent living".⁷ For the rest, receiving supports meant living in a facility or a foster home living arrangement.

Residential services in Idaho for people with developmental disabilities have been changing in recent years. In particular:

- The number of persons who reside at ISSH has been declining. In 1985, ISSH housed 317 individuals. By June 1994, that number had declined to 143.⁸
- The number of people served in privately operated ICFs/MR has been growing, from 115 in 1987 to roughly 400 today. Most of these facilities serve seven or more individuals.
- About 300 people are served in smaller 24-hour "supervised" personal care homes. These homes emerged as an alternative to other types of facility-based programs.

Many Idahoans with developmental disabilities continue to live in generic residential care facilities that are licensed as "board and care" facilities. In comparison to most other states, Idaho has a relatively small waiting "official" list for services.

In Idaho, the vast majority of residential service dollars flows into public and private ICFs/MR. These facilities serve roughly a total of 540 individuals at a cost of approximately \$42 million annually. Personal care homes presently operate under a \$45/ day per diem payment cap. Payments for residential care facilities and foster care arrangements are even lower. Spending for ICF/MR services consumes the majority of dollars spent on behalf of people with developmental disabilities in Idaho.

Idaho's residential service system for people with developmental disabilities is dominated program/facility-based models of services. While a growing number of other states are recognizing that such models contradict the overarching goal of assisting people with developmental disabilities to achieve self-determination and community membership, Idaho has continued to commit extraordinary levels of

resources to such models. For example, in most states, ICF/MR growth has been halted and the number of individuals being served in such facilities is on the decline. Idaho is one of only a few states where ICF/MR services have expanded in recent years. Supported living is playing a more important role in other states. It is in its infancy in Idaho.

DHW has recognized that the developmental disabilities service system must change. The Department launched the *Bridges to the Future* project to serve as the vehicle for promoting these change. Through *Bridges*, the Department has adopted a new vision and guiding principles for the developmental disabilities service system. *Bridges* affirms that the “rights, interests and choices of all persons with developmental disabilities are the focal point for planning”. Furthermore, a guiding principle of *Bridges* is that “supports and services encourage the development of social relationships, community life and community living skills between people with developmental disabilities and other people”. One of the central goals of *Bridges* is to “provide supports as needed and requested by consumers to live in settings they choose”.

While *Bridges* acknowledges that Idaho’s developmental disabilities service system should change and the project has served as an important vehicle for defining new system directions, Idaho still has a long way to go in defining and implementing a system of supports that is resolutely person and community-centered.

The *Bridges* project recognized that it was critical for Idaho to change how it allocated dollars for services and particularly how it employed Medicaid dollars within the developmental disabilities service system. Historically, for Idahoans with developmental disabilities, Medicaid financing has meant services in an ICF/MR or a facility-based day program. Tapping other sources of Medicaid financing more creatively was identified as a key step to promote positive system change. As a consequence, the decision was made to examine the role that the Medicaid home and community-based (HUB) waiver might play in allowing “a broader range of supports to adults who choose to live in their own homes or apartments”.

Nationwide, the Medicaid home and community-based waiver program has served as a powerful tool for the states in expanding the dollars available for community services and supports for people with developmental disabilities. In 1995, for the first time, more people (157,000) will participate in the HCB waiver program than are served in ICFs/MR of all types (141,000 individuals). This is an important milestone. Apart from the waiver program’s enabling states to acquire more federal assistance for community services, it also has permitted the states to use Medicaid dollars to pay for a progressively wider array of services and supports than ever before. In waiver programs -- unlike the ICF/MR program - services and supports may be purchased on behalf of people with mental retardation and other developmental disabilities (as well as other target population groups) independent of where they happen to reside⁹ The HCB waiver program enables the provision of services/ supports to be addressed separately from housing. Supports and services can readily be furnished to individuals who live in homes of their own.

The HCB waiver program has grown rapidly because it has demonstrated significantly lower costs than ICFs/MR in serving comparable populations. For example, the most costly HCB waiver program for people with developmental disabilities nationwide has a per capita cost that is roughly \$30,000/ participant lower than the average cost of ICF/MR services in Idaho.

Historically, many states first seized on the HCB waiver program as a means of using Medicaid dollars to finance traditional group home and day-time services. In recent years, more and more states have altered their programs to serve as vehicles for paying for family support and supported living/in-home services for individuals with developmental disabilities. The availability of Medicaid financing through the HCB waiver program has been a critical factor in the development and expansion of supported living programs in many states (including Nevada, Utah, Missouri, North Dakota, Florida and Colorado to name but a few). The waiver program enabled many states to level the funding playing field between the resources available for supported living and traditional group home services, including ICF/MR services.

Through their waiver programs, states enable supported living by crafting their programs along the following lines:

- First, they offer a wide range of services and supports. A broad support “menu” enables planning teams to craft personalized support strategies that are most attuned to the each person’s needs.
- “In-home” supports that states may offer via their waiver programs that are integral to supported living strategies include residential habilitation services (teaching people skills they need in order to take more control over their lives) and personal assistance (helping people perform everyday tasks which their disability makes it difficult for them to do on their own). States with effective HCB waiver-financed supported living programs (e.g., North Dakota) design them so that the amount of these types of supports can be tied directly to the support plan that will work best for each person.
- Increasingly, states are recognizing that “in-home” supports also must be augmented with other supports that enable people to pursue valued activities in their communities. In this vein, a growing number of states have added the coverage of “personal supports” that furnish various types of assistance to enable individuals to pursue activities outside their own home. For example, Michigan and Colorado have modified their waiver programs to permit the reimbursement of personal assistants so that waiver participants can receive training and participate in self-advocacy organizations.
- Some people have physical handicaps which must be accommodated if they are to have an accessible home. To meet these needs, states offer “environmental modifications” under their programs and pay for ramps, kitchen and bathroom modifications .
- In a similar vein, assistive technology (frequently termed “specialized medical equipment and supplies” in state waiver programs) is another coverage option that is increasingly important in enabling people to live on their own and have more control over their lives. The coverage of assistive technology often has the added benefit of reducing the long-term costs of supported living by reducing the need for hands-on staff supports.
- Finally, most states with effective supported living programs acknowledge that participants benefit from the availability of support staff to facilitate and coordinate an individual’s services and supports. In Florida’s program, for instance, the “supported living coach” plays this role. In Montana, it is the individual support coordinator.

The support capabilities described above are well-recognized by federal officials. Increasingly, these have become “mainstream” coverages under state HCB waiver programs for people with developmental disabilities. This was not always the case. Once, federal policy encouraged states to only offer services in “supervised” living arrangements. This is no longer the case.

In addition, states increasingly are promoting the use of “person-centered” planning. Since the success of supported living ultimately depends on crafting support strategies “one-person-at-a-time” and employing natural support networks, traditional interdisciplinary team service planning processes have given way to person-centered planning, which is far more compatible with the fundamental principles of supported living.

Clearly, supported living -- offering highly flexible supports to people who live in a home of their own -- has emerged over the past five years as a central direction in supporting people with developmental disabilities in their communities. Present federal policies governing the HCB waiver program are entirely compatible with best practice in supported living.

Idaho has operated a home and community-based waiver program that serves people with developmental disabilities since 1984. However, this program provided for furnishing only one service to its participants: personal care. As a result of Bridges, State officials and others recognized that changing Idaho’s HCB waiver program was integral to realizing many of the goals for the State’s revamped developmental disabilities service system -- particularly in advancing the goal of providing “supports as needed and requested by consumers to live in settings they choose” -- in other words, furnishing support living to people with developmental disabilities.

In 1993, the State split out services for people with developmental disabilities into a separate, distinct HCB waiver program.¹⁰ In 1994, DHW submitted to HCFA an amendment to expand the array of services and supports available to HCB waiver participants and thereby make it possible to craft more individualized and personalized support strategies on their behalf. In particular, residential habilitation, home modifications, assistive technology (a.k.a., “specialized medical equipment and supplies”), and chore services as well as other supports options would also be available to participants. The amendment also provided for a very modest expansion of the number of individuals (roughly 100) who could participate in the program. This amendment was quickly approved by HCFA. The amendment simply aligned Idaho’s HCB waiver program for people with developmental disabilities to more or less parallel programs in other states. The amendment is a very modest beginning in Idaho’s employing the HCB waiver program more broadly as a vehicle to flexibly support individuals in their communities.

The amendment was well-crafted. It established a broad-based definition of “residential habilitation” services which spans skill training in and outside the home as well as personal assistance. The amendment facilitates supported living approaches. While the implementing regulations had not been finalized at the time of the site visit, the

draft regulations clearly provided for the use of person-centered planning methods and stressed consumer satisfaction is a critical component of an outcome-oriented approach to assuring and enhancing quality.

Even though the amendment had modest aims, it proved to be controversial, drawing special legislative scrutiny based on the concern that it was a radical departure from the “mainstream” of developmental disabilities services in Idaho and nationwide. As a consequence, implementation was postponed. While many issues have swirled around this amendment, the controversy has revealed that there is less agreement about the future directions of Idaho’s service system than many had hoped.

To put the amendment and its ramifications in perspective, it is important to keep in mind that:

- The full implementation of the amendment still would leave Idaho in the position of serving 40% fewer individuals with developmental disabilities through its HCB waiver program relative to the State’s population than is the case nationwide.¹¹
- Idaho would still rank 47th among the 49 states that operate HCB waiver programs for people with developmental disabilities in terms of overall spending for HCB waiver services.
- Idaho would rank 42nd among the 49 states in terms of the costs per participant for HCB waiver services.
- Idaho would rank 41st among the states in terms of HCB waiver outlays relative to its population.

The HCB waiver amendment is a modest first step in changing how Idaho employs its dollars in support of people with developmental disabilities. The amendment would offer such individuals more choices than they have now. Moreover, these choices would be offered at a very modest price: roughly one-quarter of the costs of supporting individuals in a privately operated ICF/MR and one-sixth the cost of supporting a person at ISSH.

The amendment is compatible with supporting individuals in homes of their own. The amendment takes advantage of the fact that waiver services may be furnished to individuals independent of their living arrangement and, consequently, can pay for the supports that enable people to live where they choose. Services and supports can follow individuals out to wherever they may choose to live. They are not tied to a particular kind of residential living arrangement as the great bulk of residential services today in Idaho are. The amendment is the first distinct step in Idaho’s crafting a person-centered rather than a program/facility-driven system of services and supports.

It is worth pointing out that Idaho offers personal care services under its Medicaid state plan. These services are available to children and adults with developmental disabilities who live with their families or on their own. Indeed, this “program has been growing over the uses due to its popularity, and the reality that it is the only substantial in-home service available that significantly assists the person to remain in their own home”.¹² It is not known how many individuals with developmental disabilities receive personal care. However, under the state plan, an individual may receive no more than 16 hours of personal care per week. Consequently, its utility is limited, particularly for individuals with more than very modest daily support needs.¹³ By regulation, Idaho has defined personal care in “medical model” terms. Services must be prescribed by a physician and supervised by a nurse. The focus of services is assistance with activities of daily living. The provider network for personal care is weak.

Idaho has not modified its coverage of personal care services to take advantage of changes enacted by Congress in 1993 that permit a state to manage its program more flexibly. The 1993 modifications in federal law (which became effective in October 1994) enable a state to define personal care services much more along the lines of personal assistance and de-emphasize the costly medical model.

There is no doubt that the OBRA'93 provisions would permit a state to craft a highly flexible, consumer-centered personal care coverage that would enable supports to be furnished to a very broad segment of people with developmental and other disabilities. While the ready availability of personal care/personal assistance would not necessarily meet all the needs of such individuals, a broad-based, flexible coverage of personal care would enable significant numbers of individuals who are institutionalized or served in facility-based programs to obtain the supports they need in order to have a home of their own.

In summary, today, Idaho's developmental disabilities service system remains organized around dictating that people with developmental disabilities live in an agency-operated facility or someone else's home in order to receive supports. Medicaid personal care services are available to people who live on their own but only need modest levels of supports. The HCB waiver amendment is a promising but limited first step in Idaho's separating the provision of supports from questions of housing.

B. Other People with Disabilities

In Idaho, as other many other states, people with other than developmental disabilities have not gained much recognition or attention. Unfortunately, state support for services often is attached to disability labels rather than being organized on a transdisability basis even though people with disabilities of all kinds share common dreams and frequently have very similar support needs.

People with other disabilities have access to various "generic" services and supports. These include cash assistance, a Medicaid card, personal care, and vocational rehabilitation services. The State earmarks funding for independent living centers. For many people with other disabilities, these generic services enable them to live on their own in the community. For others, however, additional supports are needed. Unfortunately, people who need intensive supports to remain in their communities do not have a place to turn and, consequently, face the prospect of institutionalization, frequently in nursing facilities. Idaho offers HCB waiver services to people with disabilities who meet nursing facility level of care requirements; however, the program is limited to furnishing only extended personal care.

In some respects, there are many parallels between some of the issues that confront Idaho's services for people with developmental disabilities and those for people with other disabilities. The developmental disabilities system has labored under a facility orientation that it is now seeking to correct. The advantage that system holds is its far more extensive funding base that can be shifted over time into more valued settings. For people with other disabilities, there is an implicit reliance on facilities (nursing facilities), but shifting the funding base is a more complex task.

C. Federal Policy Change

Before turning to a discussion of policy changes that Idaho 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. 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.

To achieve 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 XXI of the Social Security Act) would be replaced by an entirely new Title ~ of the Social Security Act.
- Under Title X, 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 Medicaid statutory and regulatory requirements 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 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 the differences between the two measures resolved nor had the legislation been 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 very 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 1 1% rate at which Medicaid spending for long-term care services and supports has grown 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 and oversight of 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 would be able to readily 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 the 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 should 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 several weeks, 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., Idaho 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., permitting 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 Idaho 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. Assessment and Next Steps

The practical consequences of Idaho 's policies affecting services and supports for people with developmental and other disabilities has been to sorely constrict their choices concerning where and with whom to live. Idaho's current service delivery systems remain grounded in making the delivery of services contingent on an individual's living in a facility or someone else's home. Few dollars are available to support people who would prefer to live elsewhere.

What sort of policy and other changes should Idaho consider to realign its funding and delivery of services and supports so that people with developmental and other disabilities can exercise real choices over their own lives? There are many, ranging from broad-scale to more incremental changes. We offer the following observations and suggestions:

RECOMMENDATION: IDAHO STATE LAWS GOVERNING SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES SHOULD BE SUBSTANTIALLY REVAMPED TO REALIGN THEM WITH THE DIRECTIONS SET FORTH IN *BRIDGES TO THE FUTURE*.

A state's governing statutes are its fundamental statement of the goals that it will pursue in support of people with developmental disabilities. Idaho's basic statutes have not been thoroughly updated in several years. Mostly, these statutes concern topics such as licensure of facilities, protective services, and so forth. They do not articulate a clear mission for the overall system, particularly in adult services. This should change.

System change without the benefit of fundamental revamping of a state's laws is difficult to sustain. Moving a service system toward one that is based on a different set of values is a difficult undertaking. It is important that such change be anchored by clearly articulated public policy principles. State law should serve as the common point of reference for all parties in pursuing change.

We do not make this recommendation without recognizing that it poses its own difficulties and pitfalls. Rewriting statutes is a complex and sometimes treacherous undertaking that frequently generates its own controversies and issues. Still, it is a fundamentally important step to undertake. We note that several states have taken this step in recent years (including California (which thoroughly revamped the state's Lanterman Act in 1992), Utah, Nebraska, Kansas, and others). In each state, the central thrust was to realign the mission of the State's system with contemporary values in supporting people with developmental disabilities. Idaho should take this step. The principles that undergird *Bridges to the Future* can serve as the starting point for this legislation. State law in Idaho should affirm that people should be supported in making decisions that affect their lives and the services furnished on their behalf should support those decisions, including having a home of your own.

RECOMMENDATION: IDAHO SHOULD LAUNCH A MULTI-YEAR STRATEGY AIMED AT DEEPENING SERVICE SYSTEM UNDERSTANDING AND EXPERTISE IN SUPPORTED LIVING.

It is clear that there is uncertainty in Idaho regarding how to support people with developmental disabilities, regardless of the complexity of their disability, in living where and with whom they choose. There is lack of agreement regarding the viability of supported living, including how to structure the service system to enable supported living to become a primary support option for people. There has been only limited experience in offering supported living. Moreover, there is a lack of a broad based understanding and appreciation of the essential philosophy and technology of supported living.

The HCB waiver amendment merely set the stage for supported living; however, it does not guarantee that what emerges will be of high quality and truly responsive to the needs of people with developmental disabilities. However well-crafted the amendment and its implementing regulations might be, they do not guarantee that good supports will

be furnished. Good supports are the product of experience, “active learning”, and continuous quality improvement. DHW officials and other key stakeholders should take a variety of steps to build a stronger foundation for supported living in Idaho. In particular:

- Either in conjunction with or independent of the broad statutory reform recommended above, serious consideration should be given to incorporating provisions regarding supported living into Idaho statutes. The enactment of such legislation would give supported living co-equal statutory recognition along with other residential services. Such legislation also could go a long way in ensuring a durable, values-centered policy basis for supported living. In this light, legislation enacted in Maryland, Florida, Ohio and other states could serve as the basis of such legislation in Idaho.
- Second, we recommend that State officials strongly consider launching a multi-year supported living technical assistance project along the lines first pioneered in Florida. Since 1988, the Florida Developmental Disabilities Council has funded a Supported Living Project. This project has aided enormously in Florida in building a partnership among all key stakeholders in enabling supported living to take hold in the State. Through this project, the experiences of agencies in providing supported living have continually tapped to help guide State officials in developing the policies that guide supported living in Florida today. Moreover, the project has sponsored a technical assistance team that provides practical assistance to agencies that are embarking on supported living. The outcome of these efforts has been to build a particularly solid foundation for supported living in Florida, both with regard to the policies that guide Florida’s program and a clear, broad-based understanding of how supported living can be furnished while maintaining the essential values of person-centered supports.¹⁴
- In Idaho, achieving fundamental system change will require not only changes in funding and rules but also the willingness to commit to creating on a long-term basis an arena in which all key stakeholders are able to collaborate in learning and sharing experiences concerning supported living. Today, that arena does not exist. As a consequence, progress in system change has been and is likely to remain slow. Florida’s supported living project can serve as a useful model for Idaho in building systemwide expertise in supported living on a collaborative basis. It is important to stress that this is not a “one-time” or short-term enterprise. Building an infrastructure for supported living entails devoting time and resources to building supported living capability, knowledge and confidence in Idaho (employing the project-based approach that has proven to be so helpful in Florida)

- Finally, in a related vein, it is absolutely essential that Idaho embrace person-centered planning as its routine approach to working with people with developmental disabilities to identify where and with whom they want to live and, thus, craft the support strategies that are needed to make that happen. It is clear that the value of person-centered planning is recognized in Idaho. However, there is little that has occurred in the way of training and technical assistance to create broad-based competency in its application. This needs to change. We note that the California Department of Developmental Services has recently published extensive materials concerning person-centered planning. Under state law in California, all services plans developed on behalf of individuals with developmental disabilities now must be crafted using person-centered planning methods.

RECOMMENDATION: BY POLICY, IDAHO SHOULD CAP FACILITY-BASED SERVICES AT THEIR PRESENT LEVELS IN ORDER TO REDIRECT ALL NEW RESOURCES INTO SUPPORTING PEOPLE IN A HOME OF THEIR OWN.

Today, between ISSH and the privately-operated ICF/MR facilities, Idaho operates at roughly the national average in terms of ICF/MR bed utilization relative to its size. Neighboring states (including Montana, Wyoming, and Oregon) operate proportionately fewer such beds. ICFs/MR -- whether public or private -- are enormously expensive to operate. The majority of states have decreased their utilization of ICF/MR services. The regulations under which ICFs/MR have operated are obsolete and clearly out-of-step with contemporary values. More than 13 years of experience with the HCB waiver program have demonstrated that individuals who are eligible for ICF/MR services can be served more economically in other community settings. Indeed, in several states, agencies that operate ICFs/MR are converting to waiver funding in order to gain more flexibility.

In the past, the development of smaller community-based ICFs/MR was a significant avenue for states to access additional federal dollars to pay for developmental disabilities services. This was particularly true when federal policy made it difficult for states to expand their home and community-based waiver programs. Today, those issues have disappeared. The HCB waiver program can deliver equivalent amounts of federal assistance and enables a state to offer a wider and more flexible array of community services under less proscriptive regulations than hold sway over the ICF/MR program. Under the Medicaid changes nearing approval in Congress, states clearly must rethink how dollars are presently allocated and place a greater emphasis on lower-cost models.

Several states have formally halted (either administratively or through the enactment of state legislation) the development of new ICFs/MR Idaho should take this step as well. Beyond the ICF/MR program, Idaho should freeze its current supply of other congregate care facilities as well. Such a freeze would help focus system change efforts on broadening the availability of supported living and other small-scale living arrangements.

State officials should work pro-actively with current ICF/MR provider agencies to develop strategies for converting them into other alternatives. Such strategies have been implemented successfully in a variety of states, including Colorado, Texas, Kansas, Missouri, Oregon, and South Dakota. Such conversion initiatives frequently have stemmed from provider agency dissatisfaction with ICF/MR regulations and the desire to integrate the people served in such facilities into other community residential options that might more appropriately meet their needs. Conversion of ICFs/MR into the HCB waiver program enables agencies to operate a more seamless and flexible array of community living supports. Such conversions need to be worked out one agency at a time and with due sensitivity to local conditions and situations.

RECOMMENDATION: IDAHO SHOULD CONTINUE IMPLEMENTATION OF ITS HCB WAIVER AMENDMENT

The amendment is sound and represents exactly the right direction that Idaho should be going in order to change its service system from one that is program-based to one that is person-centered. The amendment is long overdue. Its implementation will provide important lessons to all parties in how to operate a more flexible system of supports. Even though there is the high likelihood that Congress will cap Medicaid dollars, the directions embodied in the amendment are those that Idaho should embrace. Federal funding caps will place a high premium on states shifting away from costly, facility-based program models to less costly, “one-at-a-time” support strategies. Over the long haul, Idaho must stress strategies -- like those contained in the HCB waiver amendment -- that are more cost effective than the present ICF/MR program in supporting people with developmental disabilities in their communities. Implementation of the amendment is the first step in putting those strategies into place.

RECOMMENDATION: IDAHO SHOULD CONSIDER OTHER CHANGES IN HCB SERVICES TO STRENGTHEN THEIR ROLE IN ENABLING INDIVIDUALS TO DECIDE WHERE AND WITH WHOM TO LIVE.

Absent federal policy change (we discuss alternative strategies if the Congressional proposals are enacted in a subsequent section), Idaho should earmark the maximum amount of resources possible to further expanding the HCB waiver program. If Idaho’s waiver program were roughly comparable to those in operation in other states, it would support about 700 individuals. The experiences of surrounding states (Montana, Wyoming, Washington and Oregon) strongly suggest that the waiver program can serve an even wider role in supporting Idaho’s citizens with developmental disabilities.

In July 1994, HCFA amended the regulations that govern the HCB waiver program to provide that states no longer had to justify the size and scope of their programs under what once was known as the “cold bed rule”. States may now self-determine how many individuals they wish to serve through their home and community-based waiver programs. So long as individuals meet eligibility requirements, a state may expand its program to whatever degree it elects to do so.

This federal policy change furnishes states with the opportunity to access additional federal assistance in support of people with disabilities in their communities. Previous federal policies, for example, created incentives for states to reserve their HCB waiver programs to serving only those individuals who needed the most intensive supports. Under current policy, HCB waiver financing can be accessed for a far broader range of persons. Absent significant federal policy change, Idaho should be constantly reassessing the opportunities to employ its HCB waiver program as broadly as possible.

There are two additional changes to the waiver program that Idaho should consider. 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 for the resource development specialists that DHW has located in its regions or to encourage other private agencies to offer this type of assistance.

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.¹⁵

In 1990, Congress enacted an exception to this prohibition. In particular, Congress provided in Section 1915(c)(1) states were 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).¹⁶

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 secured HCFA’s approval of an HCB waiver program amendment to add this option as well. In the case of Oregon, the live-in caregiver payment is approximately \$360/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. New Hampshire provides for a payment of \$16/day to meet live-in caregiver expenses.

This option should be seriously considered in Idaho. Housing costs are high in Idaho (and, due to in-migration and economic growth, they are increasing rapidly). Hence, it is increasingly difficult for people to find affordable housing. The live-in caregiver option offers an important opportunity to help people who require such caregivers acquire a home of their own.

RECOMMENDATION: IDAHO SHOULD ADOPT POLICIES THAT ENABLE THE DOLLARS THAT PRESENTLY ARE USED TO PAY FOR FACILITY BASED SERVICES TO FOLLOW INDIVIDUALS INTO A HOME OF THEIR OWN.

The HCB waiver program is premised on separating services from housing. Unless otherwise effectively prevented by state policy, waiver funding can follow individuals from place to place. The waiver program also enables Medicaid institutional dollars to track with people into the community. In other programs, it is sometimes more difficult to achieve the same result because dollars are earmarked for specific types of facilities. In Idaho, this occurs in the state’s funding of residential care facilities and adult foster care type settings. Payments for these services take the form of special supplements to SSI. When a person leaves a residential care facility to live in a home of his or her own, he or she loses eligibility for residential care supplement and reverts to the considerably lower supplement that Idaho pays to individuals who live “independently”. Hence, dollars that are available to people while they live in a residential care facility disappear when they leave. This obviously creates a disincentive when people are interested in acquiring their own home. Here, Idaho is sending a message to people that it is willing to spend more money when the person is placed in a facility than when the same person lives on their own.

States have considerable latitude in establishing their SSI supplementation policies (as evidence by the tremendous variety of such policies among the states). Consequently, it would seem a simple matter for Idaho simply to provide that when people with disabilities leave a residential care facility, the special supplement will follow them and remain available to purchase alternative supports. For example, if supplement dollars could be combined with personal care dollars, it seems likely that significant opportunities would be created for individuals who wished to have a home of their own realize that dream.

Unfortunately, matters are not quite so simple since implementing such a practice would create disparities in supplementation between people who had never lived in a residential care facility and those who had. Ultimately, supplementation policies must at least be even-handed for individuals in similar situations.

One way this problem can be overcome is to transfer whatever savings occur in the way of reduced supplementation payments stemming from people deciding to leave such facilities into a special non-supplementation account and, then, make these dollars available to the individuals who have left the facilities. This approach would not require that Idaho change its supplementation policies while affording residential care facility residents with disabilities increased opportunities to live in a home of their own.

RECOMMENDATION: IDAHO SHOULD REVIEW ITS PERSONAL CARE PROGRAM IN LIGHT OF THE CHANGES ENACTED BY CONGRESS IN OBRA'93.

It is evident that, in spite of its limitations, Medicaid personal care is a valued resource in Idaho. The enactment of the federal policy changes contained in OBRA'93 provide the states with an important opportunity to demedicalize their personal care programs and operate them more cost-effectively. These policy changes enable states to re-engineer their personal care coverages so that they are more person-centered and flexible and, thus, enable them to serve as more effective means to prevent institutionalization.

To date, most states have not taken an in-depth look at their personal care programs in light of the new statutory requirements. Instead, most states have adhered to their old policies, generally out of the concern that changing their personal care programs would result in increased expenditures without off-setting savings in payments for institutional or home health services. These fears stem largely from the concern that the state plan coverage of personal care is difficult to control budgetarily under present federal laws. These concerns are legitimate. Nonetheless, they may be shortsighted as well. We think it would be a mistake not to take a serious look at how personal care might play a wider role in Idaho in supporting people with developmental and other disabilities.

It is important to keep in mind that personal care/assistance furnished in even moderate amounts is the critical difference between a person's being able to live in the community or seeking placement in a frequently more expensive structured residential program. Again, the federal policy changes that have occurred in personal care offer states the opportunity to rethink the premises of their existing coverages and the role that personal care might play in reducing institutionalization across various disability groups.

In our view, broadly enabling other people with disabilities in Idaho to obtain the supports they need to live in their communities will entail seriously looking at two options. The first lies in reformulating the State's coverage of personal care to take advantage of the OBRA'93 provisions. In most respects, the issues and opportunities along these lines are no different than in terms of examining them for their relevancy in supporting people with developmental disabilities. We simply add that such a reformulation should recognize that: (a) under federal Medicaid policy, people who receive personal care can be empowered to self-direct such care, including hiring, training, and firing their attendants; and, (b) the provisions that permit personal care services to be furnished outside an individual's home offer major opportunities to adopt an "attendant" model that enables people to be supported in the activities in which they elect to participate in their communities. A reformulated coverage of personal care can be a powerful tool in promoting the independence and community presence of people with disabilities.

Our second observation is that the HCB waiver program can be employed more flexibly for people with other disabilities than Idaho does so today. For example, in fairly short order, 12 states have secured HCFA's approval to offer HCB waiver services to people with acquired brain disorders (including traumatic brain injury). Other states have crafted HCB waiver programs that target services and supports to people with physical disabilities (rather than in combination with individuals who are elderly). Through these programs, people can receive personal assistance, housing modifications, and assistive technology. It is now possible to craft HCB waiver programs for people who are mentally ill (Colorado recently secured the approval of such a program; other states are looking at this option as well). The services and supports to be offered through the modified HCB waiver program for people with developmental disabilities are not confined to that target population. Most such coverages are generic and, hence, available for other target populations.

Consequently, we recommend that key system actors in Idaho take a close look at the opportunities afforded by the HCB waiver program in expanding services and supports for people with other disabilities. We point out that such opportunities can include employing the waiver program to complement an expanded personal care benefit.

RECOMMENDATION: SHOULD THE FEDERAL POLICY CHANGES BEING CONSIDERED BY CONGRESS BE ENACTED, IDAHO SHOULD MOVE QUICKLY TO TAKE ADVANTAGE OF THE NEW FLEXIBILITY THAT WILL BE AFFORDED STATES TO MANAGE THEIR PROGRAMS MORE COST EFFECTIVELY.

The Medicaid changes that Congress appears likely to adopt will sharply restrict the flow of additional federal dollars to the states. These changes make it incumbent upon states to take an in-depth look at how they presently employ federal Medicaid dollars with a view toward shifting from higher cost services to lower cost alternatives. Absent such a shift, federal spending limitations almost certainly will lead to the outcome that waiting lists for services will grow.

In disabilities service systems, the "partnership/membership" model of supported living and personal assistance offers states the best way to make this shift while continuing to stress achieving the outcomes of self-determination and self-sufficiency for individuals. Supported living is less costly than ICF/MR services. Personal assistance is demonstrably less costly than long-term placement in a nursing facility.

Acknowledging that federal policy change will result in a severe reduction in federal dollars flowing to states, the stripping away of federal requirements and mandates also opens new possibilities to the states for redeploying federal dollars to purchase more cost-effective supports in the community, supports that can play an integral role in aiding people with disabilities to have a home of their own. In this vein, we offer the following suggestions:

- Rather than segregating Medicaid dollars from other resources, the federal policy changes will enable a state to integrate state and federal resources through single stream funding to promote a more seamless, unified approach to purchasing services and supports on behalf of individuals. Systems will no longer need to operate under distinctive rules. This can promote greater efficiency and economy.
- States will have a far better hand to regulate both the supply and cost of ICF/MR services. Where dollars are presently overallocated to such services, states will now have the latitude to limit the use of such services, including restricting eligibility to individuals with distinctive needs. This will allow Idaho to correct the present imbalance in its funding for developmental disabilities services. Over the mid-term, the State should develop a plan to reduce ICF/~~ utilization and spending and redirect dollars to less costly supported living arrangements.
- Federal policy change also will clear the way for employing co-financing strategies for both supported living and personal assistance services. Co-financing strategies blend together state/federal, individual, and family resources in order to secure the dollars necessary to purchase supports on behalf of individuals. Present Medicaid law makes such strategies very difficult and cumbersome to execute.
- Federal policy change also will mean that Idaho can craft low-risk community supports strategies. Present federal Medicaid law makes it difficult for a state to execute individualized support strategies without risking spending increases due to the program's entitlement features. Under the proposed changes, states will be in a far better position to impose reasonable funding limitations on services/supports packages and, thereby, avoid some of the problems associated with entitlement.
- Federal policy change also clears the way for states to streamline eligibility determination, service planning, and purchase of services procedures. This streamlining can reduce the overhead costs associated with the present Medicaid program. It will support capitated, single-stream, "wrap-around" funding approaches that are inherently more flexible than the "fee-for-service" methods that states must use presently. States also will have the latitude to employ vouchers and other forms of cash assistance in their programs, both of which can increase consumer choices and reduce costs.
- With respect to personal care services, the federal policy changes offer the real opportunity for a state to reprogram Medicaid dollars to underwrite cost-effective personal assistance services for people with disabilities. This includes: (a) demedicalizing personal care services; (b) shifting dollars out of expensive home health care services into personal assistance; and, (c) shifting dollars out of costly nursing facilities into personal assistance. In our view, the proposed changes in federal policy clear the way for states to sweep away the obstacles that have impeded the development and implementation of broad-scale, cost-effective personal assistance programs to replace high-cost medical models and institutional services. Shifting out of these high cost programs will at once facilitate home ownership while enabling current dollars to be used more productively. Moreover, a broadbased personal assistance strategy can be designed on a transdisability basis.

In a nutshell, federal policy change effectively will cap the overall dollars available to a state to pay for community services and supports for people with developmental disabilities. It is critical for states to rethink how their Medicaid dollars are currently deployed with an eye toward shifting toward more cost-effective options. Improving system productivity is absolutely necessary. Idaho should take advantage of the flexibility contained in the proposed changes to restructure its present disability programs to embrace the partnership/membership model.

SUMMARY

Idaho clearly needs to revamp its policies concerning how it supports people with disabilities. Today, the state is willing to spending most of its model on living arrangements that are provider agency owned and controlled. These policies run directly opposite of the fundamental notion that people with disabilities should be able to decide where and with whom they live without facing the penalty of severely reduced supports.

What other states have been able to do (and which Idaho leaders recognize) is restructure services to break down the notion that public dollars should only be spent to support people in facilities. In other words, supports should be sufficiently flexible that they can be provided regardless of living arrangement and, ultimately, be responsive to the basic decisions that individuals make about their lives. Five years ago, supported living was a novel and even “radical” concept. Today it is a reality for thousands of individuals and will be for more in the future.

Idaho’s leaders have properly recognized that changing how the State employs its HCB waiver program is integral to supporting people’s decisions concerning where and with whom they live. The HCB waiver amendment was the first step in separating service dollars from choices about housing. Other steps are needed as well, particularly in deepening and strengthening understanding of supported living.

The watershed changes that are looming in the Medicaid program should trigger a fundamental appraisal of where Idaho spends money today with an eye toward shifting out of high cost facility-based or medically-oriented services into more cost-effective supported living and personal assistance. Both of these partnership/membership models enables supports to be tailored to each individual’s circumstances while blending in natural and other community supports. Absent this shim federal funding caps will result in stagnation in Idaho’s programs.

IV. INCOMES POLICIES

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

There are 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 is 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. 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 Idaho’s policies that affect the incomes of people with disabilities. We also discuss the role that families might play in helping individuals secure a home of their own.

A Idaho’s Policies

For adults with severe disabilities, the federal SSI program guarantees a basic income floor (presently \$458/month). States may elect to supplement such SSI payments. Many states do not. Idaho has decided to make such supplement payments. Even though the amount is small (roughly \$45/month for a person living independently), this supplementation furnishes individuals with some additional income. It also has the added benefit of allowing more people with disabilities to qualify for Medicaid funded services. While Idaho is to be applauded for supplementing (particularly in light of the fact that most other states do not or provide even smaller supplements¹⁷), it needs to be kept in mind that the supplement nonetheless still leaves individuals who have no other income with only roughly one-half the dollars that federal housing guidelines specify for classifying a household as *very low income*.

As discussed in the previous section, Idaho also provides additional and more generous supplements for people who reside in residential care and other types of facilities. Since these supplements are dependent on the person’s living in a licensed facility and, at a practical level, are really payments to the operators of such facilities, these supplements do not constitute income that is available to people with disabilities once they leave the facility. Idaho’s practice in making these special payments for individuals served in non-Medicaid certified facilities is by no means unique.¹⁸ However, it is important to keep in mind that these are “vendor” payments rather than cash assistance to the individual.

Idaho offers one other type of supplement: its “essential person” supplement. In some respects, this supplement is similar to the “live-in caregiver” provisions available through the Medicaid waiver program. It is available when a person needs another individual to live with them in order to perform certain essential tasks on the person’s behalf. However, as this supplement is constructed, it has only very

limited utility as a source of dollars to augment the person's own resources. In determining the amount of the supplement, state policy takes into account the income of the "essential person". Consequently, if a live-in caregiver is paid a wage, then the amount of the essential person supplement is decreased (in fact, the caregivers income can be deemed *to* be available *to* the recipient and cause him or her *to* lose eligibility as well). The essential person supplement thereby has little value as a means to augment the individuals resources in order to meet the costs of housing.

In most public assistance programs, individuals who obtain employment will see their public assistance grant reduced by a percentage of the dollars they earn.¹⁹ Generally, Idaho's policies with regard to the treatment of earned income mirror federal policies. Idaho disregards a portion of earned income and reduces payments for one-half the remainder. As a practical matter, Idaho's policies are no more restrictive than federal policies. Similarly, Idaho's asset eligibility tests are no more restrictive than federal policy. If an individual owns a home, the value of the home is exempted when eligibility for benefits is determined.

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. Idaho has elected to follow SSI criteria for purposes of determining Medicaid eligibility but does not automatically extend eligibility.²⁰ In Idaho, generally only individuals who receive SSI or would qualify for SSI based on their disability and income are eligible for Medicaid.

Idaho's most generous policy with regard to Medicaid eligibility is in the area of institutional services. There Idaho 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, Idaho 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, Idaho has elected to not require that HCB waiver recipients contribute "Excess income" to offset the cost of services. This means that individuals have the maximum amount available to them to meet their daily living and housing expenses.²¹ In this respect, Idaho's policies promote tenure and self-sufficiency.

B. OBSERVATIONS

Among the states, Idaho's policies regarding SSI supplementation, the treatment of income and linkages to Medicaid eligibility are moderately liberal. Other states (most notably California) have more generous policies. California and Oregon, for example, provide special supplements to aid people to purchase

in-home supports. Many other states (Nevada²², Wyoming and Montana, for example) have decidedly less generous policies. Idaho's practice of making special supplementary payments to individuals in facility-based programs than people who live independently creates the wrong kind of incentives; at the same time, several other states engage in the same practice.

There is much to be said for Idaho at least entertaining a review of its income assistance policies with the view in mind of assessing their effects on people with disabilities (and other populations) in living on their own. While there are a variety 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. 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 Idaho 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 Idaho'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 regarded as having Very low income"). This means that other options may need to be considered in order to assist a person to have a home of their own. It also means that it is very important for Idaho to stress employment programs for people with disabilities.

It is worth pointing out that the policy changes that Congress is considering generally will have no effect on SSI payments for adults with severe disabilities. With regard to Medicaid eligibility, states would have a free hand in structuring eligibility criteria, including revamping eligibility to employ simple income and asset tests.

C. THE FAMILY CONNECTION

Income assistance policies (federal and state) are based on treating people with disabilities as a "one-person household". When families wish to provide additional assistance to their sons or daughters, these policies often conspire to reduce payments or even threaten eligibility for benefits. For example, if a family wishes to help a person meet ongoing living expenses by supplementing the individual's public assistance benefits, those benefits are subject to a dollar-for-dollar reduction. This is a constant source of frustration for many families, including those who are interested in helping the person obtain a permanent home of their own. Families need to constantly be alert to avoiding the result that their generosity does not impair the person's eligibility for income assistance and Medicaid-funded services.

In this regard, it is probably most helpful to describe how families can pursue their natural inclination to help without impairing a person's eligibility. In this vein, we offer the following observations:

- Generally, federal and state policies concerning eligibility for income assistance and Medicaid benefits prevent a family from giving a person money to meet his or her routine living expenses. The result of such “gifts” is a reduction in assistance. The same result can obtain when a family gives a person the money to make a down payment on a home. Any money that passes directly into the possession of the person With disabilities is deemed immediately available to the person and, thereby, offsets or cancels the public assistance benefit.
- However, a family may purchase a home on behalf of an individual and transfer title to the person. In this case, the “homestead exemption” governs. Similarly, a family may purchase a home, assume a mortgage, and rent the home to the person. The family can provide that title to the property passes to the individual once the mortgage is satisfied. Similarly, two or more families can combine their resources to help obtain housing.
- Families can participate in helping a person acquire a home under some of the recent arrangements that have been worked out by Fannie Mae and being replicated by state housing finance authorities. Such participation can help buy down the amount to be mortgaged without necessarily impairing eligibility for benefits.
- Estate planning also enables families to set aside dollars in a fashion that enables them to be employed on behalf of a person with disabilities without impairing eligibility for public assistance or other benefits. Many states have adopted “self-sufficiency” trust or similar legislation to provide for this option. Federal policy spells out the requirements for how such arrangements need to be structured in order to prevent the impairment of eligibility.²³

There are complexities involved in all these arrangements. It is vital that they be undertaken prudently. Most certainly, the Idaho home ownership project should make information available to families regarding how they might employ these options.

Some times the issue of guardianship arises with relation to home ownership. Often, families are guardians of people with disabilities. Some forms of guardianship can impair the person's ability to acquire a home, particularly in executing a mortgage agreement. If a person has a guardian, then lenders are not certain that the individual can be held to mortgage agreement. The trend among the states has to been to replace “all or nothing” guardianship laws with limited guardianship arrangements which enable guardianship to be tailored to individual needs and circumstances with proper safeguards.

The National Home of Your Own Alliance is pulling together information on these topics. The Idaho project should employ this information to inform families about the options available to them.

As a final note, changes in federal Medicaid policy will enable public agencies and families to explore a wider range of co-financing/co-funding strategies for services and supports. Under present federal policy, families who would be willing to pay for part of the costs of ongoing supports are effectively prevented from doing so. Under the proposals presently being considered, co-funding strategies appear to be feasible. Some states already are exploring alternatives along these lines. New Jersey, for example, recently set aside dollars that are specifically earmarked for joint-funding initiatives with families.

SUMMARY

Within the confines of federal law and policy, Idaho has not adopted incomes policies that pose extraordinary impediments to people obtaining a home of their own. Other states have more hostile policies. Idaho does furnish a supplement to SSI; people who earn income are able to retain some part of it; and, Idaho's HCB waiver financial eligibility policies do not work in opposition to people being able to garner whatever resources they can to meet their housing and other living expenses.

In an ideal world, Idaho would have more generous policies (particularly in light of escalating housing costs) and would offer people who live on their own at least the same level of assistance that the state is willing to pay when they enter a residential care facility. If it did, likely fewer people would go into such facilities.

In today's world, policymakers must keep firmly in mind that many individuals with disabilities have very, very low incomes. This means that it is enormously important to assist them in securing real jobs (and, hence, break out of the poverty cycle) and, sometimes, to take extraordinary steps to make housing more affordable to them.

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 permitting them to acquire housing at “below market” costs) or organizations (in the form of providing them with other sorts of subsidies in order to permit them to build more affordable housing). In many respects, 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 Idaho, state, local, and non-profit agencies 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 Idaho 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 Idaho to both public and private home ownership resources. We offer comments about the general tenor of housing policy in Idaho 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 IDAHO

As a general matter Idaho has not elected to pursue an aggressive affordable housing policy. The Idaho Housing Authority (IDA) has contracted with the federal Department of Housing and Urban Development to administer HUD dollars that flow to Idaho. IHA also sells tax exempt mortgage revenue bonds to enable low-income families and individuals to obtain below market mortgage financing.

The extent of Idaho’s efforts in helping low income individuals obtain affordable housing largely depends on federal housing programs. Idaho does not operate a set of distinct housing programs on its own to complement or fill the numerous gaps in the federal programs. This is a particularly serious problem in light of the rapidly rising costs

of housing in Idaho and the prospects that federal housing dollars have been caught up in the squeeze on discretionary federal spending that is occurring as a result of efforts to trim the federal deficit.²⁴

From a policy perspective, this means that Idaho is both the beneficiary and the captive of federal housing policies which at once can be important cogs in enabling people with disabilities to have a home of their own (as in the case of HUD Section 8 certificates) but also subsidize the development of facilities. For example, the State Planning Council on Developmental Disabilities has observed that the “demand for rental assistance far exceeds the supply”. Federal funding of housing carries Idaho only so far in assisting people in finding affordable housing. There is every prospect that federal housing dollars will be slashed. Moreover, Idaho’s nearly exclusive reliance on federal dollars means that it has greater difficulty in working around Federal policies that work in opposition to strategies that make housing affordable for people with disabilities (for example, policies against unrelated people sharing a unit create problems for people for whom a roommate might be a source of support).

The absence of stand-alone state funding for affordable housing is a serious problem in Idaho. This substantially limits developing more flexible approaches or addressing needs that are not and are increasingly unlikely to be addressed through federal programs. Nor does this situation seem likely to change in the near term. The State’s Housing Trust Fund has gone unfunded for a considerable period of time.

The State’s draft 1995 Consolidated Plan (prepared by IHA) identifies a wide variety of ways that Idaho can do a better job with the resources it has on hand. Certainly, IHA’s participation in the HOYO project will aid in building better approaches to assisting people with disabilities in employing available assistance. It is particularly encouraging that IHA is considering setting aside federal HOME funds that will be available to the project to pursue its home ownership objectives. Equally important are the linkages that are being established with the private sector. All these steps need to be pursued aggressively.

We note that the 1995 Comprehensive Plan makes reference to the fact that Idaho needs to explore whether mutual housing strategies would be of assistance in promoting the development of more affordable housing. Mutual housing associations and cooperatives, in fact, are worthwhile avenues of exploration. Connecticut’s policies and experiences in this regard are particularly relevant. At the same time, there are other policy steps that should be seriously considered specific to people with disabilities that should be entertained.

B. POLICY STEPS

Failing a major shift in Idaho housing policies that would see the State initiate its own strategies to make housing more affordable for very low income people, the question must be asked: “What steps can Idaho 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. In Idaho, that wait can be anywhere from two months to two years. 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 various policies and steps that Idaho 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. Other practical steps include:

- *Furnishing Dared Subsidies to Individuals* Florida, Connecticut, Oregon, New York, and North Dakota (to name a few states) have recognized that, despite best efforts to locate affordable housing and access all available avenues of assistance, many people with disabilities still lack the resources necessary to cover basic living expenses (housing, utilities, food and so forth). In response, these states have decided to augment people’s resources with state dollars to make up the difference. In the case of both Florida and Connecticut, these states have gone the extra step of making one-time grants or loans to individuals to help them meet security deposit and the other expenses associated with setting up their home. In each instance, the additional subsidies that are provided are closely regulated. Individuals need to exhaust their own and other available resources first before they may qualify for a housing subsidy. Connecticut, for example, regulates the allowable amount rent of individuals that may be subsidized to no more than HUD fair rental standards for the area in which the person lives. In each case, the State involved has recognized that SSI and other resources available to individuals frequently will not be sufficient to cover their living expenses. Typically, the resulting subsidies are modest and, often times, not permanent. In a very direct way, these states are filling the considerable resource gaps that prevent individuals from having a home of their own. Moreover, people with disabilities, properly, continue to be responsible for meeting as much of their living expenses as they are able. This mechanism also aids in bridging the period before a person qualifies for some more permanent type of assistance.

Clearly, this approach is an income subsidy intended to make up for the fundamental fact that SSI and SSI supplements (as well as other sources of assistance) still leave people impoverished. At the same time, these policies also recognize that, absent such subsidies, individuals are likely to remain housed in frequently more expensive facility-based programs (and, which themselves, receive various forms of state and federal funds that subsidize the cost of housing). From a total cost perspective, furnishing such subsidies can be very cost effective. We recommend that Idaho seriously consider this option, especially for areas that have particularly high housing costs. Both Florida’s²⁵ and Connecticut’s policies in this arena can serve as templates for adopting a similar policy in Idaho.

- *Down Payment/Closing Cost Assistance* 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) 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. The amortized cost of these subsidies is very small, particularly in comparison to the subsidies that states routinely make to owners/operators of facility-based programs.

- *Roommates* Congregate living arrangements force people with disabilities to live with other people with disabilities whom they did not select. In reaction, sometimes supported living is portrayed as acceptable when the person with disabilities lives with no one else. The reaction is understandable given literally decades of history during which people were not even consulted about where and with whom they would like to live.

As a practical matter, when a person has a roommate (whether a person with or without a disability), it can be easier for the individual to afford a home of their own. As a matter of preference, many people would like to share a living arrangement with someone else. Many people with disabilities have friends with whom they would like to share a living arrangement. In supported living, many people receive supports from a live-in caregiver who is a paid support person who might share in the living expenses.

We raise the topic of roommates not to suggest that it is a universal solution to making housing more affordable. It is not. 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.

The foregoing are ways to directly attack the problem of housing affordability for people with disabilities. Idaho should give them careful consideration.

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.

In Idaho, work already is underway in the first two of these areas. The Idaho HOYO project is compiling information about housing resources and has committed to making this an ongoing activity. DHW has hired resource specialists for each of its regions who are charged with learning about local housing and programs. Both of these are key steps.

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. 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, consequently, 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 Idaho to follow. Each option can work equally well, depending on circumstances and locality. 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. Another alternative lies in strengthening and broadening the roles and responsibilities of the DHW regional ACCESS units to serve as hubs of support coordination and assistance for people with disabilities.

D. SUMMARY

From a policy standpoint, Idaho faces some serious challenges in the arena of housing. A rapidly growing population, escalation in housing prices, and the prospect that federal housing aid is likely to deteriorate mean that the present shortages of affordable housing for low income individuals (including many people with disabilities) may well worsen. Alternative, gap-filling state programs have not been established. Clearly, this will place a premium on finding new approaches to housing finance in Idaho.

The State's present circumstances mean that serious consideration ought to be given to alternatives geared specifically to assisting people with disabilities in having a home of their own. We have provided examples of some potential steps that Idaho might take.

Finally, certainly if it is true that the current shortages in affordable housing in Idaho might worsen, it becomes even more important to marshal resources to ensure that people with disabilities who need help in locating housing and accessing housing assistance have access to an "agent" who can aid them in that task.

VI. PULLING THE PIECES TOGETHER

This report has covered a wide variety of topics. Clearly, there are many steps that Idaho can take in order to improve opportunities for people with developmental disabilities to have a home of their own. Here, we offer some brief observations and suggestions aimed at sorting these suggestions into a near-term and long-term agenda for policy change.

A THE NEAR TERM AGENDA

What are the steps that Idaho should put on its near term agenda? We believe that there are three steps that deserve immediate attention:

- *First, all stakeholders need to make a strong commitment! to the precepts of supported living* This commitment is not widespread today. The State is heavily invested in facility-based programs. In some quarters, a changeover to supported living is viewed as threatening. Supported living is not a “shared vision”. It is viewed as outside the “mainstream”. There is uncertainty and a lack of confidence about “supported living”. In this regard, it will be important to give supported living special project status in order to overcome these problems. A project structured along the lines of the Florida initiative can serve as the vehicle to not only address the concerns about supported living but also establish a foundation for system change.
- *Second, Idaho should proceed with the implementation of the HCB waiver amendment as the first step in restructuring services and supports on a partnership/ membership model basis.* The amendment is sound; it is the correct policy direction for Idaho. This implementation should occur within an active learning environment that recognizes and addresses problems as they arise. With the potential that future federal Medicaid payments to Idaho might be reduced, it is very important that the state be prepared to extend the approach embodied in the HCB waiver program to its overall developmental disabilities service system. The essence of this approach is tailoring services and supports to individual needs, preferences and circumstances to promote greater cost-effectiveness and system productivity.
- *Third, the State should give strong consideration to providing special, ear-marked housing subsidies to individuals to permit them to secure a home of their own* At a practical level, many people will need additional financial assistance in order to secure a place of their own. Frequently, the amount of assistance that is needed is modest. That amount can be reduced by employing the HCB waiver live-in caregiver option and encouraging roommate arrangements. We believe that the assistance programs in operation in Connecticut and Florida are well-crafted to ensure accountability and personal responsibility. Idaho should establish a similar assistance program to help overcome impediments to people securing a home of their own. It is important to keep in mind that the effect of such a program is to neutralize the biases in federal and state policy toward facility-based programs.
- *fourth the State should fully appraise the impacts and opportunities afforded by tile federal/ Medicaid policy changes that Congress appears likely to enact.* The new federal policy context will enable Idaho to “zero-base” its present programs and chart a course that stresses low-cost, tailored supports rather than continuing to rely on high cost facility-based programs. This appraisal should be conducted as quickly as possible.

B. THE LONGER TERM AGENDA

The longer-term agenda in Idaho should concentrate on the following:

- ***From a strategic standpoint the State must steadily realign resources away from facility-based residential services to a more agile person-centered system of community supports.*** Given the real potential that federal Medicaid dollars will be capped, Idaho will be less able to sustain a high-cost, facility-based service system. This new fiscal climate will place a premium on developing systems where public support dollars complement other natural and community supports. Hence, the State should pursue strategies that decouple dollars from particular program models. This will be a difficult process. It will be vital to establish a constructive rather than a confrontational climate in which these changes can take place.
- ***This changeover should be framed in State law and policy.*** Idaho should revamp its laws to sanction a “person-centered rather than a “program-based” philosophy. Again, we note that the major statutory changes adopted in other states can serve as templates for the changes Idaho should make in its statutes.
- ***With regard to income support policies Idaho should take a look at them with an eye toward ensuring that people with disabilities who choose to live on their own are accorded equal treatment with those served in other settings.*** While we acknowledge that such a change has potential financial implications, individuals should not be disadvantaged when they simply wish to have a home of their own.
- ***Lastly, Idaho must plan and implement a permanent infrastructure in support of people having a home of their own and being able to access both public and private sources of housing assistance.*** Valuable lessons are being learned in Idaho through the current project. Such lessons, however, can prove transitory unless system actors think ahead to establishing a more permanent infrastructure for assistance at both the state and local levels. Very clearly, the DHW regional ACCESS offices potentially can play an important role in this regard as can permanent alliances among state agencies.

BACKNOTES

- 1 Robert Prouty and K Charlie Lakin (eds.) (June 1995). Residential Services for Persons with Developmental Disabilities :Status and Trends Through 1990. Minneapolis: University of Minnesota, Research and Training Center on Community Living.
- 2 David Braddock, Richard Hemp, Lynn Bachelder, and Glenn Fujiara (Draft: March 1994). The State of the States in Developmental Disabilities. Chicago: University of Chicago at Illinois, Institute on Disability and Human Development.
- 3 Ibid.
- 4 Troy Mangan, Ellen M. Blake, Robert W. Prouty, and K Charlie Lakin Dune 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.
- 5 Ibid. Nationwide, about 47% of ad people with developmental disabilities who receive residential services are serve in settings of six-beds or less; in Idaho, these “small” settings constitute only 38% of the total
- 6 Residential care facilities are “room and board” facilities. There are three levels of such facilities. They are paid for with special SSI supplements
- 7 Bureau of Developmental Disabilities, DHW (September 1994). Director of Residential Facilities for Persons with Developmental Disabilities
- 8 CRCSL
- 9 The chief and obvious exception is that waiver dollars cannot pay for institutional services.
- 10 Prior to taking this step, Idaho’s waiver program served a variety of target populations. The State, then, decided to cover personal care services under its Medicaid state plan. The waiver program was altered to pay for extended personal care over and above the limitations set out in the stale plan. HCB waiver services for people with developmental disabilities under this arrangement largely took the form of paying for “personal care home” services where individuals received more intensive supervision and personal care services than provided for in the state plan
- 11 NASDDDS, 1995 HCB Waiver Survey.
- 12 Idaho State Council on Developmental Disabilities
- 13 Persons with more intensive needs (and who qualify for nursing home or ICF/MR level of care) are expected to be served under the State’s HCB waiver programs.
- 14 See for example, A Guide to Supported Living (February 1995) published by the Department of Health and Rehabilitative Services Supported Living Project

15 While there is a certain “logic” to this differential, 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

16 In June 1995, HCFA modified its standardized HCB waiver application format to permit states to more readily include the “live-in caregiver” option in their programs.

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

18 In Hawaii, for example, nearly the same structure exists. The state provides special supplements to individuals who live in “domiciliary care facilities”; as in Idaho, there are three “levels” of such facilities.

19 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.

20 Under Section 1634 of the Social Security Act, a state may elect that, when the Social Security Administration determines that the person is eligible for Medicaid, a Medicaid card will be issued automatically. In states that do not elect the Section 1634 option, individuals need to make a separate application for Medicaid.

21 In technical terms, Idaho has established a “maintenance allowance” for HCB waiver participants equal to 300% of SSI. Under federal policy, individuals may retain this maintenance allowance in order to meet their living expenses. 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.

22 Nevada, for example, supplements SSI for individuals who are aged or blind but not persons with other disabilities.

23 The national office of The Arc has available a host of materials related to trust arrangements. A good overview of the interplay between eligibility for SSI and other programs and trust arrangements is contained in One Step Ahead. Resource Planning People With Disability Who Rely on Supplemental Security Income and Medical Assistance, available from the Wisconsin Council on Developmental Disabilities.

24 As in the case of Medicaid, it is necessary to point out that the 104th Congress is likely to make some major changes in federal housing programs, including bundling up dollars and sending them to the states in the form of a block grant. It is impossible to predict exactly what changes Congress ultimately will approve.

25 Florida’s Supporting Living Guide spells out the State’s procedures for determining the amounts of these subsidies.