

Supported Living Project: *A Final Report*



Submitted to
Idaho Council on Developmental Disabilities

by
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December, 2002

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Points of view expressed herein do
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Idaho Council on Developmental Disabilities
or the State of Idaho.

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Preface

Idaho has two Home and Community Based Services (HCBS) waivers for persons with developmental disabilities. One waiver is exclusively for individuals who leave the Idaho State School and Hospital (ISSH) or for those individuals who would otherwise require that intensive level of care. At last review, 61 individuals use the ISSH waiver and 32 of them reside in their own homes or apartments. The second waiver is for all other adults with developmental disabilities who meet the eligibility requirements (those who need the equivalent of the ICF/MR level of care). Approximately 1,050 Idahoans are served through this waiver including 87 whom reside in their own homes or apartments and 157 who live in the home of a non-paid care provider.¹

Through a Request for Quotations (RFQ), the Idaho Council on Developmental Disabilities announced the availability of funds to support the development of a consensus position on how to amend Idaho's two Medicaid HCBS waivers for persons with developmental disabilities that would increase the effectiveness of programs designed to support people in their own homes or apartments. The RFQ stated that the recommendations must be cost-effective, facilitate self-determination and be developed through a combination of research and discussion with stakeholders.

Idaho submitted its HCBS waivers to the Centers for Medicare and Medicaid Services (CMS) in July 2002. The RFQ also indicated that the information and recommendations from by this report would be presented to policymakers for consideration in amending the waivers at a later date.

¹ Adapted from the Idaho Governor's Council RFQ.

Introduction

An emerging, national and international trend in developmental services is the shift towards a supports paradigm. Embodied in this new set of rules for providing services are the principles of individual choice and self-determination. Asbaugh, Bradley and Blaney (1994) suggest that the paradigm is most clearly identified by: (1) a system in which individuals with developmental disabilities have the option of choosing among available supports and providers (including friends and family); (2) service coordinators provide support and guidance to inform these choices; (3) ongoing self-advocacy training; (4) multiple sources of supports from which to choose; and (5) rather than "fixing people," the emphasis is on integration and inclusion.

Supported living is clearly a major service element of the emerging supports paradigm. However, in Idaho as in many states, that supports paradigm is evolving slowly. As stated by Asbaugh, Bradley and Blaney (1994), *in order for the supports paradigm to take center stage, state developmental disabilities systems and provider agencies must change. Current organizational structures, cultures, and political environments are designed to make the institutional and community paradigms; they are not designed to further the supports paradigm.* This is the challenge for Idahoans. It will take collaborative leadership and a strong resolve to redesign the service system in a way that organizational structures, cultures and political environments are focused on supporting individuals with developmental disabilities. Making changes to Idaho's current waiver(s) is, in fact, only a small part of that redesign.

Supported living has been defined "as a set of ideas and practices regarding a chance to live safely and well in a home of one's own (alone or with others); respect for preferences and choice; a lifestyle that makes sense to the person; as much self-

reliance as possible; and receiving the personalized services and supports to make it happen (Allen, Shea and Associates, 1995).” In order to generate a discussion of waiver-funded supported living services and develop some considerations for ways to increase their use in Idaho, we completed a number of activities, including:

- review of waivers from over twenty states² ;
- interviews with ‘stakeholders’ from Idaho Falls to Couer d’Alene over the course of several weeks;
- creation of a website with documents for review and comment by ‘stakeholders’;
- contact with waiver specialists regarding ‘best practices’;
- development of a list-serv contact with State Medicaid representatives to collect waivers for review and to further explore relevant issues;
- review of a non-representative sample of individual support plans; and
- research into ‘best practices’ of supported living services, individual needs assessment and service planning.

While many documents and conversations provided to us were more general in nature regarding other waiver and service delivery issues, we have tried assiduously to stick to the original intent of the contract. To reiterate, our ‘charge’ was to look at and report on waiver-funded supported living services.

² **Note:** While we reviewed over twenty waivers, we report on a much smaller number in this report. We have included information from waivers that represents both a diversity of approaches and examples that support considerations for waiver and policy changes found later in the document.

Due to time and funding parameters, this report relies on the general impressions of stakeholders as well as some quantitative documentation of identified challenges. A more specific and evidence-based report on the service needs and resources of Idahoans with developmental disabilities will be forthcoming in the report from the *Real Choice Systems Change* project. On a final note, this report is presented in a conversational and non-technical way whenever possible in order to increase reader interest and accessibility.

Waiver-Funded Services for People with Developmental Disabilities in Idaho

Introduction.

It is important for anyone looking at Idaho's current waivers, to understand some of the history and context that surrounds them. This section of the document is a summary of information and notes gathered from stakeholders and waiver specialists.

A Brief History.

Until the early 1990s, Idaho operated a single HCBS waiver program. The program supplemented personal care services available through the regular Medicaid program. Waiver participants could receive additional hours over and above the hour limit in the regular Medicaid program. The single program served older persons and people with disabilities. Some people with developmental disabilities were served in this program.

In 1991, Idaho decided to set up a stand-alone waiver program for people with developmental disabilities. This is the present HCB-DD waiver program. When first established, Idaho modeled the program after Indiana's developmental disabilities waiver program design. The services that the program offers have not changed appreciably since then except for the 1999 addition of "adult day care" services. In 1996, the state added a "model" HCBS waiver program (HCB-ISSH) to underwrite community placements for individuals from the Idaho State School and Hospital (ISSH). The HCB-ISSH waiver mirrors the HCB-DD waiver program in the services it offers. Payment rates are higher under this program than HCB-DD.

Present Waiver Configuration.

The present HCB-DD program operates in tandem with two other “regular” Medicaid services. In Idaho, service coordination (case management) is a Medicaid state plan benefit (through the targeted case management option). Idaho calls these services “targeted service coordination” (TSC).

In 2001, about 2,200 people received TSC. TSC is not confined to HCB-DD or HCB-ISSH waiver participants and is available to any Medicaid-eligible adult with a developmental disability³. By rule, TSC services must be furnished by the employees of licensed and certified developmental disabilities agencies. An agency that furnishes other direct services to an individual cannot also furnish TSC to the person.

Idaho offers “developmental disability agency” services under its regular Medicaid program (as rehabilitation services). Waiver participants and other Medicaid eligible persons who use these services can receive: (a) psychotherapy; (b) speech/hearing; (c) physical therapy, and (d) developmental and occupational therapy services. In nearly all other states, “developmental therapy services are furnished as “day habilitation” through the HCBS waiver programs. Idaho is one of a handful of states that furnishes these types of services under its regular Medicaid program⁴.

The HCB-DD waiver program supports adults with developmental disabilities age 18 and over. The state’s financial eligibility rules are relatively liberal (people can qualify for waiver services who have incomes up to 300% of SSI). The state does require individuals to turn over income to offset the costs of waiver services.

³ In addition to individuals with developmental disabilities, Idaho also provides TSC for individuals with a mental illness, personal care recipients and children.

⁴ During the late 1980s, CMS (HCFA) ruled that states could only furnish “developmental therapy”-type services through an HCBS waiver or as part of ICF/MR services. Congress intervened to protect states such as Idaho that covered these services under the state plan.

The state amended its waiver program twice in 1999. It added adult day care, dropped private duty nursing services, the age at which individuals could receive services was lowered from 21 to 18, and mandatory six-month team meetings were dropped in favor of requiring monthly meetings between each participant and his/her service coordinator.

Currently, individuals enter the waiver program via ACCESS ("Access to Care Coordination, Evaluation, and Services and Supports) Units located at seven regional developmental disabilities offices. The local ACCESS Unit serves as the single point of entry for the waiver program and other developmental disabilities services. The ACCESS Unit determines whether the person is eligible under the state's definition of developmental disabilities (the state uses the federal definition of developmental disabilities) and arranges for the development of a service plan.

When an individual seeks HCB waiver services, the ACCESS unit is also responsible for assembling the necessary information to determine whether a person meets ICF/MR level of care. Individuals must have a comprehensive assessment and the State uses the Scales of Independent Behavior-Revised (SIB-R). Individuals who enter the HCB-DD program must then select a service coordinator. The service coordinator then works with the individual, family and/or guardian, and service providers to develop a service plan. The service coordinator is responsible for 'costing' the service plan. The plan is submitted to the ACCESS unit for review and authorization. The ACCESS unit reviews the plan to ensure that it is cost-effective.

The Idaho waiver program was designed to furnish services and supports to individuals who live in their own home or a family home. The program does not cover services in congregate group home-type settings. The program provides for "supported living" arrangements for up to three individuals and adult foster care-type ("alternate family

home") arrangements for up to two individuals. Services also can be brought into the family home if the person lives with a family.

The HCB-DD services that people most commonly receive are "residential habilitation" and "adult day care." The use of other waiver services is relatively low with the exception of behavior consultation/crisis management. In 2001, the average cost of waiver services in Idaho was approximately \$25,000 per participant. This was about 30% below the nationwide average. However, the costs of regular Medicaid services furnished to Idaho participants (about \$20,000 per participant) are well-above levels typically observed in other states. These costs include TSC charges plus developmental disabilities agency services costs.

Based on the renewal application for the HCB-DD waiver program, the total (waiver plus other Medicaid costs, including service coordination and day services) average annual cost of supporting a person is about \$45,000 while the total cost of supporting a person in a private ICF/MR is roughly \$77,000⁵. Idaho does not impose an HCB waiver "cost cap" that would preclude individuals whose costs exceed the ICF/MR average from participating. In theory, this means that people with especially high support needs can be supported in the waiver program.

The HCB-DD waiver program presently offers the following services:

- ***Respite*** may be furnished in the person's own place of residence, in the respite caregiver's residence or the community (paid on an hourly and daily basis).
- ***Residential Habilitation*** -includes personal assistance, skills training, and other types of habilitation (e.g., self-direction, socialization and so forth). Planning teams have flexibility to identify the specific services and supports for each participant. Idaho permits family members to be paid to furnish residential habilitation services. Residential services are furnished by certified residential

⁵ The HCB-DD cost effectiveness calculation is between waiver services and the costs of private, non-state ICF/MR services. ISSH ICF/MR costs are excluded because they serve as the point of cost comparison in the HCB-ISSH waiver program.

habilitation agencies and may also be furnished by "independent providers" so long as these providers affiliate with a certified agency. Residential habilitation may be furnished in the person's own home, supported living arrangements, the family home, or alternate family. According to data furnished to the University of Minnesota, in 2001 more than 80% of waiver participants are served in alternate family homes⁶. Another 150 were identified as supported in homes of their own. Payment for residential habilitation varies by type of provider and size of living arrangement and can be made for hours of service or a daily rate.

- ***Supported Employment*** must be furnished by an accredited agency. Idaho pays for such services at a standard hourly rate. The amount of supported employment services is limited to 40 hours/week.
- ***Environmental Accessibility Adaptations*** include home modifications and can be vendored to community contractors.
- ***Skilled Nursing*** provides "intermittent oversight" of a participant's medical condition or health status and/or supervision of the medical services provided by a provider.
- ***Transportation*** is paid on a per mile basis.
- ***Specialized Medical Equipment and Supplies*** includes equipment and assistive technology of various types.
- ***Chore Services*** include heavy household maintenance and minor home repairs in a home rented or owned by the participant.
- ***Personal Emergency Response Systems (PERS)***
- ***Home Delivered Meals*** permits providing 1-2 prepared meals per day.
- ***Behavior Consultation/Crisis Management*** "provides direct consultation and clinical evaluation of individuals who are currently experiencing or may be expected to experience, a psychological, behavioral, or emotional crisis." This service may provide training and staff development related to the needs of a recipient. These services also provide for emergency back-up involving the direct support of the individual in crisis."
- ***Adult Day Care*** is defined as a "supervised, structured day program, outside the home of the participant or provider that offers one or more of a variety of social, recreational, health activities, supervision for safety, and assistance with activities of daily living." This service typically supplements residential habilitation, which is provided inside a person's home.

⁶ Robert Prouty, Gary Smith, and K. Charlie Lakin (eds.) (2002). **Residential Services for Persons with Developmental Disabilities: Status and Trends through 2001**. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living.

Except for residential habilitation, adult day care and behavior/crisis services, use of most other waiver services appears to be low based on the figures contained in the HCB-DD waiver renewal application. Most stakeholders interviewed suggest that this is likely due to the domination of alternate family homes as the principal living arrangement.

Pilot Efforts

The State has been working on several initiatives (e.g., Developmental Disabilities/Mental Health Service Delivery Project or SDP, Traumatic Brain Injury waiver services) that are focused simultaneously on controlling costs and implementing best practices. With respect to the waiver program, key initiatives include:

- **Independent Assessment Provider (IAP).** An independent contractor entity would be employed to conduct comprehensive assessments of individuals, assigning them to a support level, and conducting “utilization management” over the services and supports they are authorized to receive. The IAP would arrange for the development of each person’s service plan. The main effect of this change appears to be the shift to a third-party in order to standardize and “objectify” assessment and resource assignment across the state.
- **Resource Assignment.** The state has been considering a methodology to assign waiver participants to funding tiers. Individuals would be assigned to tiers based their scores via the administration of the “Scales of Independent Behavior-Revised” (SIB-R) tool plus information garnered from other assessments that take into account dimensions not addressed by the SIB-R. The funding tiers under consideration would take the form of dollar ranges rather than fixed amounts. Within these ranges, the IAP would set a fixed

dollar amount that would be the dollar amount of the services and supports that could be authorized in a person's plan.

- **Prior Authorization.** This would require that regional Access Units determine the need for and authorize the level of use of developmental therapy.

Olmstead Planning.

In July 1999, the Supreme Court issued the *Olmstead v. L. C.* decision. The Court's decision challenges Federal, state, and local governments to develop more opportunities for individuals with disabilities through more accessible systems of cost-effective community-based services. As indicated by the Department of Health and Human Services (HCBS Primer, 2000), the Medicaid program *can be an important resource to assist states in meeting the principles set out in the Olmstead decision.*

In order to meet this challenge, The State of Idaho convened the Community Integration Committee. While not asked to determine state compliance with the Olmstead decision, the group developed a series of recommendations regarding ways that the State could facilitate the development of community-based services. The following recommendations from the Subcommittee on Developmental Disabilities are relevant to the questions and issues outlined in the Council's request for this report:

- 1) Educate stakeholders on the value of community integration, regardless of ability.
- 2) Devote Department resources to the development of services and support options for people with intense support needs.
- 3) Explore an HCBS waiver for children.

- 4) Explore raising the HCBS/ISSH cost effectiveness cap to allow waiver participants to use supported living without a roommate when their needs require a higher cost effectiveness cap.

- 5) Explore bundling of services into a single daily rate or billing code and simplifying documentation requirements. This could save considerable time and expense, making it easier for supported living providers to serve more consumers and meet more diverse needs.

Other Factors.

Until FY 1999 - 2000, Idaho's use of the waiver program did not change much from year to year. The number of people served ranged from 300-400. In part, this was because the state was finding its way in operating a waiver program. Some stakeholders opposed expanding the program and the Legislature was not especially supportive of increasing its use. However, in FY 1999 - 2000, the number of HCB-DD participants increased from 463 to 735. The next year (2001) the HCB-DD program expanded again to 970 persons. In that same year, 61 individuals participated in the HCB-ISSH program.

Other factors of interest include:

- The Idaho State School and Hospital currently serves about 110 people. There is a relatively high admission and community placement of individuals through ISSH, principally because of the short-term admission of people with challenging behaviors or court involvement. There is no plan to further downsize or close ISSH.

- There are currently about 65 ICFs/MR operated by private providers. These facilities served 474 people in 2001. As in other states, this residential option was developed in the 1980s to help reduce the size of ISSH. From time to time,

there have been discussions in Idaho about bringing these facilities under the waiver to create a more seamless service system.

- Altogether (based on University of Minnesota figures for 2001), Idaho provides residential services for about 3,300 people. In terms of comparison, this is a relatively large number of people for a state of Idaho's size. Most of these people (roughly 2,000) live in state-funded facilities (i.e., they are not waiver-funded or ICFs/MR).
- Idaho has an extensive, Medicaid funded day service program. There are some 57 providers throughout the state. In 2001, about 3,900 people received these services. Since 1996, the number of people receiving these services has more than doubled.
- Idaho ranked 16th (Braddock) in terms of fiscal effort in 2000. Spending for developmental disabilities services accelerated post-1996. The waiver, developmental disabilities agency services, and case management have all increased at a rapid rate. Spending for ICFs/MR has also increased even though there has not been much change in the number of people.
- In the past two years, the Legislature made it clear that it wanted spending for developmental services to be more tightly controlled. This backdrop facilitated the implementation of the "Developmental Disabilities/Mental Health Service Delivery Project." The project has focused on piloting ways to control spending have been through "utilization management."
- Developmental disabilities services are located in the Division of Family and Community Services. Family and Children Services spans child welfare, early

intervention, mental health, and developmental disabilities. The Division maintains seven regional offices where intake and eligibility services are provided. In addition, there are regional offices that manage Medicaid resources allocated for services and supports of people with developmental disabilities.

What are Supported Living Services?

Introduction.

The Council requested a discussion of a number of core questions and issues regarding supported living. The following sections of the document provide: (1) a discussion of a core question or issue; (2) examples (e.g., best practices, policies) from other states whenever possible; (3) what was learned from Idahoans regarding the question or issue; and finally (5) short and long-term considerations for stakeholders.

A Definition.

Prior to any discussion here of specific issues involved in providing supported living services in Idaho, it's important to let the reader know what constitute those services by definition. The ARC US (1997) defines supported living as:

Usually involves individuals living in homes or apartments of their own. The person may live alone or choose to live with a roommate versus being placed with others. Supported living often involves partnerships between individuals with disabilities, their families and professionals in making decisions about where and how the person wishes to live. Focus is on giving utmost attention to the desires of the person with a disability in how he or she would like to live, and to support the individual in having control over choices of lifestyle. People in supported living may need little or no services from professionals, or they may need 24-hour personal care. The kind and amount of supports are tailored to the individual's needs.

The State of Florida (with a strong tradition of waiver-funded supported living services) defines supported living services as *an opportunity for adults with developmental disabilities to choose where, how and with whom they live*. Further, that *people receive personalized supports needed to maintain their own private home*. To distinguish it from other living options, they indicate that the

characteristics of supported living include⁷:

- housing (control of the threshold through ownership, lease or rent) is separate from support services (if an individual's needs change, he or she does not have to move to change providers of supports and services);
- capacity to live independently is not a requirement for service eligibility;
- services are individualized, flexible, and responsive to individual needs (based on individual preferences, are flexible and centered around a person's strengths and abilities, not their disabilities);
- personal choice and control is maximized; (control of life experiences, choices and outcomes are in the hands of the individual, not a program);and
- natural (e.g., friend, relatives, neighbors, community members) supports are emphasized (links to natural supports in the neighborhood and community are encouraged and tend to occur when the number of paid staff is significantly outnumbered by the number of non-paid friends, family and acquaintances).

In *Creating Individual Supports for People with Developmental Disabilities* (1994), the common features of a number of supported living services studied by the authors were described as: (1) paid support provide by live-in or on-call staff, roommates or companions, attendants, or neighbors; (2) individualization and flexibility; (3) a focus on the individual; (4) a belief that people live in homes not facilities; and (5) individual and family involvement in planning and quality assurance.

⁷ Adapted from information provided by the Florida Department of Children and Families, Office of Developmental Disabilities (2002).

What is the 'Paradigm' for Supported Living?

The following provides an outline of the 'typical' *conditions* for what is described as supported living services:

Living in a Home of One's Own

One condition of supported living services is that individuals live in a home of their own choosing and under their control. It's important that the person's name (not the service agency) is on the lease, rental agreement or mortgage. This practice also serves to separate a person's housing needs from their needs for support.

Interdependence

Supported living services value interdependence. The goal is not complete independence from other people. Instead, the goal is to help people experience the interdependency or give and take of relationships within families, neighborhoods and communities. [The goal is relationships that will support people in ways that everyone needs support.]

Flexible and Tailored Services and Supports

Supported living services and supports are patterned differently for each person. Each pattern is unique and not repeatable. This method of providing services contrasts with programs that use a curriculum model that everyone moves through regardless of their service needs. Supported living services value the choices, needs, and satisfaction of people with developmental disabilities in addition to time-limited, measurable, instructional and behavioral goals.

Sharing Power

Supported living services require that the agency, the individuals they support and the individual's family, friends, and service coordinator work collaboratively as a team to make decisions. Ultimately, the individual who receives services has the loudest voice in all decisions that affect his or her life and their services.

How are Supported Living Service Plans Developed?

Typically, service coordination or supported living agencies use a person-centered assessment process to get to know someone and his or her support needs. The process includes the individual and his or her circle of support and others who know and care about the person. Whichever process is used (e.g., Essential Lifestyle Planning), agencies want to discover:

- what is important to the person in his/her everyday life;
- what people, places, activities and things are important;
- what routines and rituals are important;
- what the person can do for him/herself and what he/she needs support to do;
- how the person would like support provided (e.g., time of day, qualities of staff, frequency, order to doing things);
- kinds of support the person will need to stay healthy and safe;
- how the person communicates his/her needs and desires; and
- what the agency and others will need to know and do to help the individual live in a way that makes sense for them.

This assessment process is done initially to help develop a support plan, but the learning and discovery process continues throughout the relationship between the agency and the individual.

Presence of Factors Influencing Positive Outcomes.

In 1995, Allen, Shea & Associates completed an evaluation of California's Community Supported Living Arrangements pilot. After interviewing 151 individuals using supported living services, surveying family members, interviewing service coordinators, supported living service providers, members of community monitoring teams, we learned that positive outcomes for individuals with developmental

disabilities in supported living are more likely to certain factors are present. We offer a summary of those factors here with some slight adaptation for this report:

Individuals communicate their preferences, likes and dislikes to others; assume responsibility for what they can do for themselves; work effectively with others; and, make responsible decisions.

Families and friends want to be involved in supportive ways; are collaborative team members; live close enough; have high expectations; advocate; monitor relationships between support staff and the individual; and, accept a reasonable level of risk.

Supported living agencies are person-centered and get to know the person well; individualize services and supports; honor choices in selecting a place to live, lifestyle, and the type and amount of support and who provides it; stand by the people they serve and share responsibility for working through challenging situations; are collaborative team members; work to develop community and natural supports; advocate; know and use the public and generic service system; work to maximize efficiency in the use of human and financial resources; monitor relationships between support staff and the individual; and, have a strong belief in action, commitment and perseverance.

Service coordinators spend enough time to know someone; are collaborative team members; understand the service system, in general, and patterns of service for supported living; advocate; are trained and supported in person-centered planning; and, monitor relationships between support staff and the individual.

State and regional developmental disabilities staff support preferences and encourage choice of supported living service provider; provide service coordinators or supported living agencies adequate time and funding to develop individualized

support plans; use a broad-based system of outreach and an open selection process; select agency liaisons who know about (and value) supported living; encourage and develop service coordinators who are collaborative team members; value the person-centered planning process; provide technical assistance to service users and providers; support the acquisition and maintenance of adaptive equipment; advocate for generic services; disseminate resource information; and, recognize the long-term savings of providing adequate support services.

State and regional Medicaid staff develop agency certification standards that establish service user rights, honor choice, stress collaborative teamwork, and describe minimum protections (e.g., background checks, 24-hour emergency response, individual quality assurance plans); develop policies that allow flexibility in negotiating rates; provide technical assistance on important issues (e.g., risk and choice, cost containment); advocate at a state level for generic services; and, disseminate resource information (e.g., communication technologies, adaptive equipment).

The presence of the factors listed above will lead to the following *valued outcomes for Idahoans with developmental disabilities*:

Choice

Individuals experience a choice of *lifestyle* (e.g., work, living, relationships, activities) and *support* (e.g., agencies, services and support as needed) arranged in a way that works best for them.

Support Needs

Individuals receive the kinds of services and support that are needed, from people requested, at times when they are preferred. There are no disruptions in service when needs or preferences change.

Relationships/Natural Supports

Individuals have a social network of paid and unpaid people who support him or her as a member of the community. In addition, these are non-exploitative relationships.

Health and Safety

Individuals live in a safe home and neighborhood and receive services and supports from people who care. Environmental controls and adaptive equipment are available as needed.

Generic Services

Individuals have access to and receive services available to other members of the community as needed (e.g., personal care services, Housing Assistance, education, recreation, health, transportation, adaptive equipment).

Overview of Waiver-Funded Supported Living Services

Introduction.

The Council proposal asked for an overview of national supported living models and how services are delivered. There is one widely recognized model of supported living services and that occurs when *staff* (selected by the individual the individual with the developmental disability and others as needed) *provide support to people in homes of their own that they have chosen.*

Variations Across States.

Nationally, there are a number of programs that label the services they provide as *supported living*. While they may provide exemplary services, they do not provide supported living services. In fact, some are basically one or two person group homes and others support people who live with their families. The variations across states with respect to waiver-funded supported living generally revolve around the following:

- **Access Limitations.** One variation across states is that some limit access to supported living services through cost or service prohibitions. For example, some states (e.g., Illinois) significantly limit payments or supported living (e.g., setting ceilings that are far lower than the cost of other eligible living options). Other states limit access by excluding individuals who need 24 hour a day support. It follows then that these states limit access to supported living to individuals who do not need very intensive supports.

- **Community Supports.** Some states fund *helpers* - people who take care of assorted everyday tasks at home and in the community for people in supported living (in addition to typical personal care services). In Florida, these helpers are called supported living coaches and in California, they are called community support facilitators. They help people with tasks like dealing with the utility company, going to the local community college for a class, or joining a club or organization, etc.
- **Housing subsidies.** Some states (e.g., New York and Connecticut) provide extra *non-Medicaid* dollars to people for housing assistance. Supported living is more feasible if necessary housing support dollars are available. Where housing dollars are not available, the most typical way of dealing with the high costs of housing is that individuals have roommates (with or without disabilities) in order to have their own place.

The Midland Model.

The Midland County (Michigan) model is often described as setting the bar for the ideal and most effective system of providing supported living services (whether fully or partially waiver-funded). Five agencies in that county, each with a different and discrete role, collaborate to support people with developmental disabilities living in their own homes. The agencies represent mental health, independent living, State, and advocacy agencies as well as a private funding source.

This model is known for the following attributes:

- Agencies work together as a team in helping individuals and their families design supports around the individual. Resources are organized around the person and that has decreased typical 'turf' issues.
- The design of the service plan is based on an independent person-centered planning process. That is, independent facilitators are contracted to support

the personal futures planning process. Professional assessments are used when needed. People who know the individual well, help identify the desires, dreams, goals and needs of the person.

- Circles of friends are integral to the design and provision of support. In fact, it is one of the services available to individuals as *Circles of Friends: facilitation of a group of family, friends, and professionals that make up a supportive network for an individual with a disability*. About two-thirds of the individuals served have Circles of Friends.
- Home ownership is promoted throughout the service system. In fact, a private funding source was established solely for the purpose of assisting people in owning their own homes.

Example of a Capped Service.

Individuals in Illinois (that typically live with their families) using waiver-funded supported living services are limited to a maximum cost of \$1,500 per month. If this service is selected, the recipient may not use any other developmental service (except for Vocational Rehabilitation).

Eligibility includes age 18 or older, a need for continuous supports and services in order to remain in their own home. A team leader helps develop and coordinate a service plan that can include any of the following: direct support worker; respite; developmental training, supported employment or senior day services; nursing; behavior therapy or counseling; speech, physical or occupational therapy; or transportation.

Example of a Non 24-Hour Service.

The waiver-funded service in Colorado stresses individual choice and the availability of supports needed to assist individuals to participate in the typical activities of

community life. In addition to supporting individuals in their own homes, the service is designed to provide supports to an individual in the family.

To be eligible for the waiver-funded service, the individual must be 18, pay for their own room and board expenses, be in control of their own living arrangement and cannot require 24-hour supervision on an ongoing basis (exceptions are made for certain short-term situations). Eligibility does not necessarily guarantee the availability of resources. An individual may be put on a waiting list until funds become available. The Colorado program is designed to use a variety of natural non-paid supports and generic community services.

A key component of the service is the individualized support plan (ISP). The purpose of the ISP is to identify both lifestyle choices and health and safety needs. The assessment process that drives the plan includes: a description of necessary community and natural supports; needs and preferences of the individual that support living more independently; and, identifying the safety, nutritional and medical needs of the individual.

The array of services for supported living services includes: (1) personal assistance (e.g., personal care, household maintenance and mentorship activities in addition to services available under the State Plan and not duplicative); (2) professional services (e.g., occupational and physical therapy; behavioral services, and other services not covered under the State Plan; (3) dental services (e.g., comprehensive dental treatment not covered under Medicaid State Plan benefits); (4) day habilitation and community accessibility services; (5) environmental engineering (e.g., home modification, assistive technology, emergency response systems, mobility aids, specialized medical equipment, in excess of what is available under Medicaid State Plan Benefits); (6) transportation; and, (7) 24-hour emergency assistance.

Individuals can also choose to use the Supported Living Consultation (SLC) service option. Individuals may choose a family member or friend to volunteer or an agency SLC can be assigned. The SLC is responsible for coordinating supported living services and supports, assist the individual with maintaining his or her health and safety, completing required documentation and paperwork, assessment and development of an individual safety plan (e.g., emergency assistance, medication, nutrition).

At this time, there is no individual budget process and no *cash out* feature to allow individuals to purchase services on their own. The range of annual costs is estimated to be from \$13,000 to \$35,000.

Example of a Community Support Service⁸.

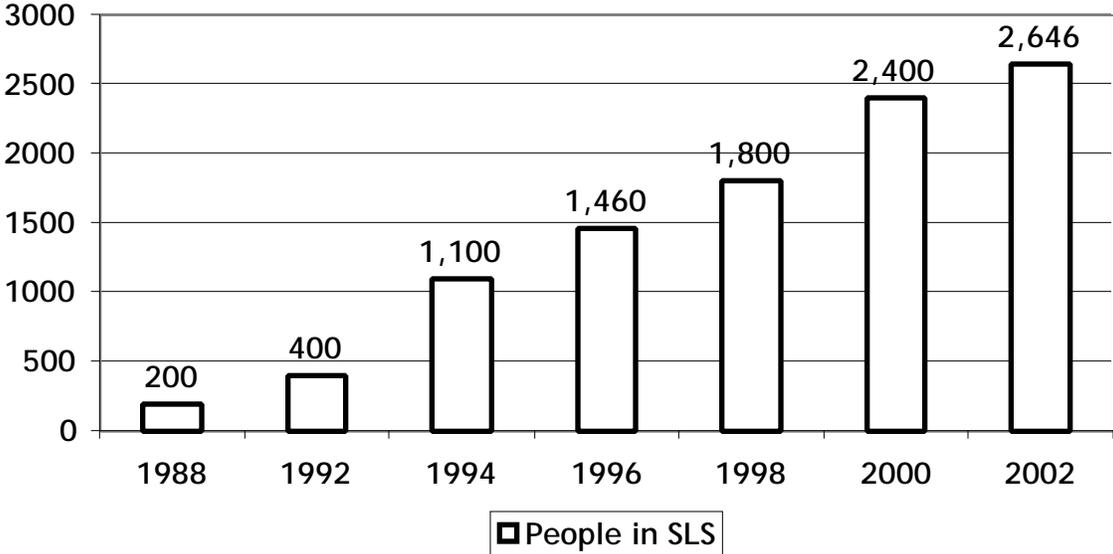
Florida was one of the original eight state recipients of the Community Supported Living Arrangements federal grant in the early 1990s. Since that time, they have successfully transferred that grant-funded service into their HCBS waiver. In Florida⁹, adults in supported living select from a wide variety of supports and services. Each person has a support coordinator and a supported living coach, and both are Medicaid waiver services. Based on need, individuals can receive in-home supports, personal care, companion, and various other in and out-of-home supports.

At this time, the average cost in Florida for supported living is around \$21,000 per year for all services offered. The upper range of service costs is about \$60,000 per year. In-home supports (from 8 to 24 hours per day) are offered in to individuals that live in their own home. There is some concern with 24-hour supports regarding the inherent risk of moving towards a staff-centered living experience and away from a person centered, individualized arrangement.

⁸ In the course of this project, we have learned a lot about the differences between what states write in their waivers and their implementation. Whenever possible, we tried to learn what we could about those differences. For example, we have presented above two waivers that provide examples of capped and non-24 hour services. While the intent of the waivers serve as an example, we understand that both waivers are used primarily to support individuals living with their families and not in their own homes.

⁹ Adapted from personal correspondence with a Medicaid representative from Florida Department of Children and Families, Division of Developmental Disabilities,

Growth in Supported Living Services in Florida



What follows is a brief outline of those services¹⁰. We have included it in this report as it represents a well thought out approach and appears to adhere most consistently to the original tenets of supported living.

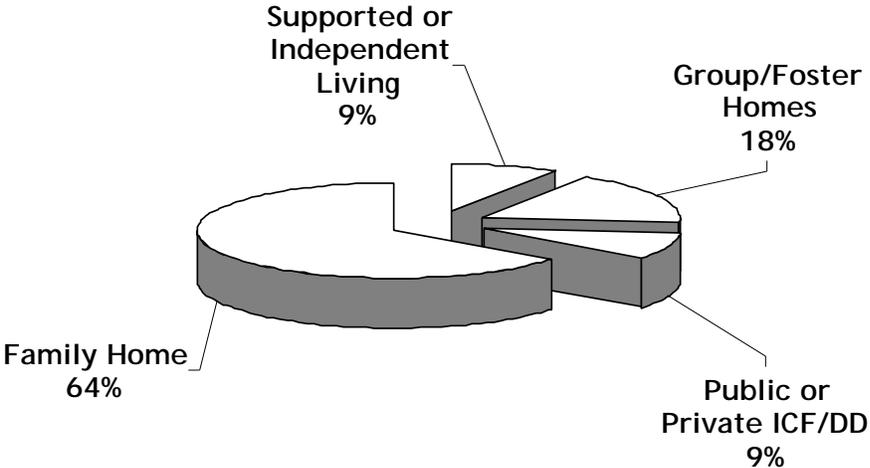
Eligibility for Services. Supported living coaching services are limited to adults (age 18 or over) who rent or own their own homes or apartments in the community. The supported living provider or the provider’s immediate family cannot be the individual’s landlord or have any interest in the ownership of the housing. If renting, the name of the individual receiving supported living services must appear on the lease either singularly, with a roommate or a guarantor.

Definition of services. In Florida, supported living services mean the provision of supports necessary for an adult who has a developmental disability to establish, live

¹⁰ Adapted from materials provided by the Florida Department of Children and Families, Division of Developmental Disabilities

in and maintain a household of their choosing in the community. This includes supported living coaching and other supports. Supported living coaching are services that provide training and assistance in a variety of activities to support individuals who live in their own homes or apartments. This may include assistance with finding appropriate housing, the acquisition, retention or improvement of skills related to activities of daily living such as personal hygiene and grooming, household chores, meal preparation, shopping, personal finances and the social and adaptive skills necessary to enable individuals to reside on their own.

Distribution of Living Options in Florida



Assessment of needs. The process for assessing service needs includes three components. The first is the *Functional Community Assessment*¹¹ that provides the basis for identifying the types of training, assistance and the intensity of support needed by the individual. The assessment addresses all areas of daily life including relationships, medical and health concerns, personal care, household and money management, community mobility, recreation and leisure. The supported living provider is responsible for helping the individual complete the functional community

¹¹ We understand that the State is in the process of developing a new assessment process.

assessment prior to his or her move to a supported living arrangement. The assessment is updated annually.

The *Housing Survey* is the basis for looking at a prospective home to ensure that it is safe for the individual. The supported living coach provides a copy of the completed survey for the housing that was selected by the individual to the individual's support coordinator. It is updated quarterly and available for review by the waiver support coordinator at the time of the waiver support coordinator's quarterly home visit. The quarterly update of the Housing Survey includes a review of the individual's overall status of health, safety and well-being.

A *Financial Profile* is an analysis of the costs and income sources associated with maintaining a balanced monthly budget for the individual. The analysis provides eligibility information regarding the need for monthly subsidy and initial start-up costs. It is also used to determine strategies for assisting the individual in managing his or her resources. If the financial profile indicates a need for a subsidy, it's submitted to the waiver support coordinator and must be approved by the district.

Provider Qualifications. Providers of supported living coaching services may be either independent vendors or agency vendors. Independent vendors and employees of agencies who provide these services must have a bachelor's degree, an associate's degree and two years of experience, or related experience on a year-for-year basis for required college education.

Training. Agency employees and independent vendors are required to attend at least twelve hours of pre-service training prior to assuming job responsibilities, and eight hours of annual in-service training. Providers must also complete training covering AIDS/HIV once every two years.

Service Limits. Supported living coaching services are limited to the amount,

duration and scope of the services described on the individual's support plan and current approved cost plan/service authorization. Services must be provided at the time and place mutually agreed to by the individual and provider. The provider shall have an on-call system in place that allows individuals access to services for emergency assistance 24 hours-per-day, 7 days-per-week.

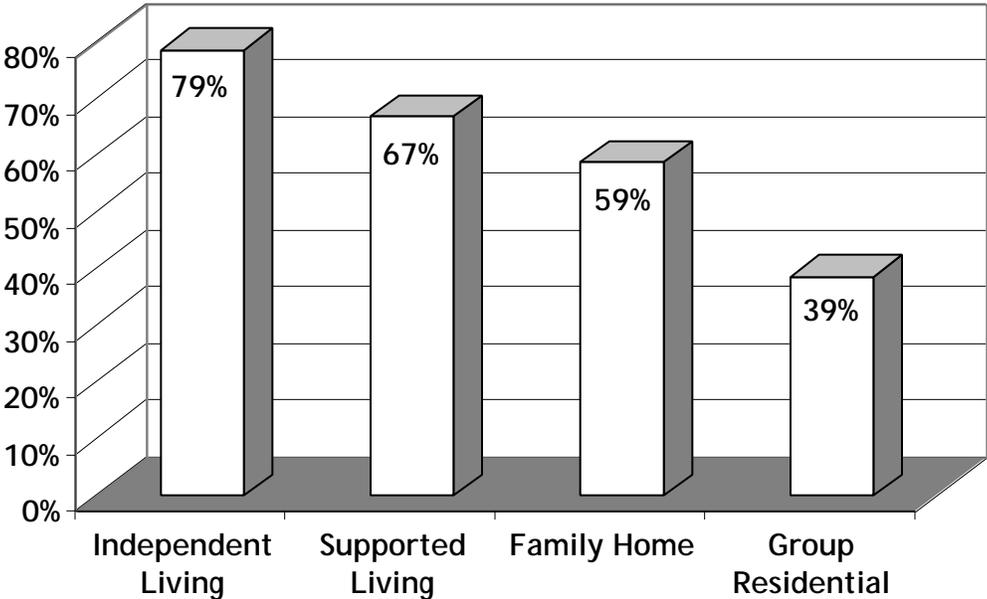
Individuals receiving supported living coaching services live where and with whom they choose. However, individuals must live with no more than two other people who have developmental disabilities and must have control over the household and its daily routines. Individuals who live in family homes, foster homes or group homes are not eligible for these services unless the individuals are in the process of moving into their own homes or apartments.

Service Outcomes. Florida has developed some basic service outcomes used to set goals for each SLS provider and to determine through monitoring and review the effectiveness of service provision. Any and all of the projected outcomes may be selected by the district and can be altered or changed to better reflect participant needs. The district and the provider develop interpretive guidelines that describe criteria for determining provider achievement of the outcomes and to detail how the outcomes will be evaluated and measured. The outcomes include:

- Individuals are the lessee or owner of the home in which they reside.
- Achieve a satisfactory or better rating on of individual satisfaction surveys.
- Individuals live in homes with no more than two other individuals with developmental disabilities and in areas in which persons with disabilities account for no more than 10 percent of the houses or 10 percent of the units in an apartment complex.
- Individuals demonstrate an increase in abilities, self-sufficiency, and changes in their lives consistent with their support plan goal(s).

- Individuals achieve an increased level of community inclusion or community involvement (e.g., building and/or maintaining natural support systems, establishing or increasing community connections).
- Individuals have maximum freedom of choice in all areas of their lives as evidenced by setting personal goals, being fully informed about service options and making all possible decisions with regard to the conduct of their lives.

Percent of Personal Outcomes Achieved by Living Option



Steering a Straight Course. As in other states, there are temptations in Florida to move away from the basic tenets of supported living (e.g., 3 or more persons living together). Some see the possibilities of cost savings and higher profitability absent licensing requirements. The state has worked hard to keep services aligned with the original design of community supported living arrangements (CSLA).

On an individual level, the supported living coach and the planning team (or circle of support) are critical in keeping sight of the goal to provide person-centered services

to individuals living in their own home. Additional factors are ongoing monitoring of how providers support individuals and training in the policies and practices of supported living services.

Another factor in the state's success in crafting and maintaining waiver-funding supported living services is the Florida Governor's Council. The council has made significant investments in training and in leading a major culture shift towards an individual supports paradigm.

Non Waiver-Funded Housing Subsidies.

As previously mentioned, some states offer non-Medicaid assistance for individuals who live in their own homes. The State of Connecticut Department of Mental Retardation operates a subsidy program assist individuals in meeting the housing costs attributable to acquiring and using a personal home in the community. The subsidy is available to any person who is: eligible for Department of Mental Retardation services; directly responsible for payment of his or her housing costs; does not have sufficient income or assets to pay for his or her total housing costs; and who has pursued all other funding sources. The subsidy can be used for the following: rent (including payment for mutual housing and limited equity cooperatives); security deposits; utility costs; personal property insurance; and costs related to routine maintenance.

Homes must meet safety standards and rents must be reasonable (e.g., less than 130 percent of the fair market rate). The subsidy amount is similar to that available to a person on Section 8, that is, the person is expected to contribute approximately 38 percent of his or her total income towards housing costs.

The State of Florida offers both funds for start-up and a monthly cost-of-living subsidy. Start-up funds can run up to \$2,000 and monthly subsidies range from \$50 to \$500 or more per month, depending on individual need. Funds for these subsidies,

however, are limited, as they are not covered under the current 1915c waiver. The State is working on an Independence Plus waiver that will allow people to *cash in* their services and that will possibly provide an additional source of funding for living expenses.

Service Reimbursement Structures

Introduction.

The Council asked for a discussion of the strengths and weaknesses of service reimbursement structures (fee-for-service, daily individualized rate, bundled services, etc.) for supported living as well as the prevailing thought about which is believed to work best.

Major Methods of Reimbursement for Waiver Services.¹²

Medicaid policy gives states considerable latitude in the methods they use to make payments for home and community services. Thus, states may (and do) use any of a wide range of methods to determine the amount they will pay for home and community services. States may also use different methods for different services. Methods in current use include:

- **Fee-for-Service Price Schedules.** The state establishes a uniform payment rate that applies to all providers of a service. Personal assistance attendant services are frequently reimbursed on this basis.
- **Cost-Based Payments.** The state bases payment rates on the allowable costs incurred by the specific provider, usually accompanied by upper limits on costs to encourage cost-effective service provision.
- **Negotiated Rates.** The state bases payment rates on the specific provider's actual or expected service costs.
- **Difficulty-of-Care Payments/Rates.** The state pays providers amounts that vary

¹² Excerpted from Understanding Medicaid Home and Community Services: A Primer (HHS, 2000).

based on expected differences in the intensity of services and supports specific individuals require. Such methods seek to improve access to services for individuals with particularly complex needs and conditions.

- **Market-Based Payments.** The state purchases goods and services from generic sources (e.g., installation of a wheelchair ramp, emergency response system, etc).

Service Reimbursement and Waiver-Funded Supported Living Services.

Within the payment methods listed above, there are fundamentally two ways to provide supported living under a waiver program. One way is to assemble distinct waiver services into the person's plan of care (service plan). Employing this approach, a "supported living" plan is developed composed of x amount of service a, y amount of service b, and z amount of service c and so forth. In other words, a package of supports from the waiver service menu is assembled to create a supported living service.

In essence, this is how supported living is done in states like Wisconsin (and other states as well). Wisconsin does not offer a service labeled supported living, but many people are in supported living arrangements. Supported living is provided to individuals by pulling together personal assistance and other covered benefits. When this approach is used, the reimbursement structure de facto is a fee-for-service.

Bundled Services.

The second approach is to cover supported living as a distinct service. This approach always involves a "bundled" service definition (e.g., services a, b, and c are all included in the supported living service definition). The scope of the bundle can be

narrow or wide (as noted in the earlier section on variations in supported living services across states). When this approach is used, reimbursement is most typically made on a daily rate basis, although in a few states it is fee-for-service (e.g., payments are by hour of service rendered).

Daily Rates.

There are two ways to construct a daily rate. The first is an "individualized rate." In this method, daily rates are set by determining the person's supported living plan and then pricing the plan based on the hours of supports that will be provided and convert the result to a daily rate.

This model has been employed in North Dakota and Missouri. The North Dakota method prices direct worker time, contains an allowance for supervision and the coordination of supports, and a flat fee for administrative costs. The daily, individualized rate is derived from hours authorized in the service plan. The payment to the provider is "prospective" in the same fashion as daily rates for group home or other similar services. This type of system gives providers some leeway. Hours can be shifted among individuals without affecting the daily rate.

North Dakota reconciles payments with provider costs every year. If the provider has not spent the dollars authorized for direct supports across all individuals served by the agency, the state recovers excess payments above a specified threshold. Administrative payments are truly prospective. North Dakota's reimbursement system operates in tandem with an especially well-designed set of provider accounting requirements that enable the separation of direct costs from overhead costs.

The second daily rate model is not entirely individualized. Some states set daily rates for supported living on a “tier basis.” People are classified and grouped into categories and the same rate is paid for each person in the tier. The benefit of this approach is that it is simple. The chief drawback is also that it is simple.

California uses an “individualized rate” system that varies from region to region in methodology. All regions provide funding to service providers for the assessment of service needs and development of a support plan. Some regions negotiate an individual budget from that plan. Others use a multi-leveled tier system that allows for a waiver of the tiers based on exceptions (e.g., significant health or behavioral issues),

Which Works Best?

The answer to the question of *which works best* is that it depends. A daily rate/bundled service approach anticipates that the payment will be made to a single provider agency that, in turn, is responsible for arranging or directly providing all the necessary supports. If instead, the approach is to create supported living by assembling services from the waiver menu (e.g., supported living is not covered as a distinct service), by definition a State is stuck with a *fee-for-service* model because services can't wrap everything up into a single package and multiple providers might be involved.

One waiver specialist indicates that the approach that works best is an individualized daily rate directly tied to the person's service/supported living plan. For example, the North Dakota approach (discussed later in this document). Payments are directly tied to each person's plan and there is reasonably good accountability. However, only a few other states have adopted this model because it is more labor intensive than developing a flat rate. The model may also create concern because it appears to

be open-ended, although it could be linked into tiers or threshold amounts for cost control/containment purposes.

Daily rates are relatively provider friendly because they allow shifting resources among individuals. The main issue with daily rates revolves around accountability - are the volume of services and supports upon which the rate was based actually delivered? So, it's important to make sure that there is accountability built into the reimbursement structure (e.g., the provider delivers the contracted volume of direct services).

Adequacy of Rates.

Whatever method of service reimbursement structure is used by a State, the adequacy of rates is critical. It must be such that it attracts agencies to offer the service and direct support professionals to provide it. The two most onerous outcomes of inadequate rates are: (1) few or no choices of providers for individuals; and (2) high turnover rates of support staff.

The Research and Training Center on Rural Rehabilitation Services (2002) recently completed a study of direct Service Staff Turnover in Supported Living Arrangements. Their preliminary findings and observations included the following:

- High turnover rates mean that some providers of supported living services may be replacing almost their entire direct service workforces each year.
- This instability imposes significant costs on each provider for recruiting, screening, and training replacement workers.
- It also adversely affects the quality of care provided to individuals served by community providers. Although the relationship requires further study, caregiver

continuity appears to be an important factor in the health of an individual with developmental disabilities.

- The range of direct service staff wages reported in the study of seven agencies ranged from \$5.75 to \$13 per hour. Employees worked an average of nine months (range of 6-12 months) before becoming eligible for wage increases. Pay increases were low, averaging about 3.4%.
- The annual average turnover rate was 77% and it ranged from 10% to 144%. The corporation reporting the highest turnover rate also had the lowest starting wage.
- Other studies have identified determinants of turnover rates including a) lack of management and/or coworker support; b) inadequate wages and/or benefits; c) inadequate training for handling challenging situations; d) poor working conditions (e.g., stress, ambiguous roles, inadequate consumer care); d) lack of career advancement opportunities; and e) other factors (risk of injury, fear of liability lawsuits, etc.).
- Cost figures varied widely, ranging from a low of \$939 to a high of \$5,662, with an average cost of \$2,627 per worker exit. Training and vacancy costs were consistently the highest costs. Training averaged about 38% of the worker-replacement costs and vacancy pay was about 25% of the total. Service providers would recognize significant savings if new employee training and overtime pay to remaining workers were reduced.
- If it is assumed that a one dollar (\$1) per hour pay increase could reduce turnover to zero, the increased annual per-employee cost to each provider would be \$2,080 (2,080 hours times \$1) - the break-even point where higher wage costs would almost equal average turnover costs. Additional benefits might

include increased worker productivity, referral of friends to employers, and higher worker morale. In practice turnover is never zero - employees are promoted, terminated, laid-off, retired or leave due to personal, health, and family reasons.

- The Rural Health Institute study suggests additional study needed to look at the effects of turnover on the health status of individuals with developmental disabilities. Further, the Institute indicates some findings regarding turnover rates and the level of disability and age of individuals supported. That is, younger and less disabled individuals appear to have lower rates of turnover among support staff than do older and more disabled (e.g., challenging behavior, medical issues) individuals. This may indicate the need for differential rates of pay in order to equalize this turnover factor.

Bundling Services and Billing Practices

Introduction.

In its report requirements, the Council requested some information about what specific SLS services are most frequently 'bundled together' and what are typical billing processes.

Typical Service 'Bundles' for Supported Living.

The services typically bundled together for supported living are personal care or personal assistance, skill training (habilitation), homemaker or chore helper, and transportation. Typically, these services are delivered within the person's living arrangement. However, the scope of supported living can be broadened to include supports outside the living arrangement (e.g., support in building community connections).

There are two main benefits of bundling. One is simplification. Usually a single agency provides or arranges for supported living. When services are not bundled, service documentation and billing are more complicated. In addition, frequently, one worker is involved with the individual and is providing many different kinds of supports. Bundling helps avoid the support worker having to record time for each separate task.

Examples of 'Bundled' Waiver Definitions of Supported Living.

The following are three examples of 'bundled' waiver-funded supported living services (typically found in Section 11t *Other Services* of the waiver):

California

“Supported Living Services includes any individually designed service, or assessment of the need for service, which assists an individual consumer to live in a home that they own or lease, which is not licensed, nor the place of residence of a parent or conservator, with support available as often and for as long as it its needed. The purposes of supported living services include: assisting the consumer to make fundamental life decisions, while also supporting and facilitating the consumer in dealing with the consequences of those decisions, building critical and durable relationships with other individuals, choosing where and with whom to live, and controlling the character and appearance of the environment within their home. Supported living services are tailored to meet the individual's evolving needs and preferences for support without having to move from the home of their choice.

Examples of supported living services activities include: assistance with common daily living activities; meal preparation, including planning, shopping, cooking, and storage activities; routine household activities aimed at maintaining a clean and safe home; locating and scheduling appropriate medical services, acquiring, using, and caring for canine and other animal companions specifically trained to provide assistance; selecting and moving into a home; locating and choosing suitable house mates; acquiring household furnishings; settling disputes with landlords; becoming aware of and effectively using the transportation, police, fire, and emergency help available in the community to the general public; managing personal financial affairs; recruiting, screening, hiring, training, supervising, and dismissing personal attendants; dealing with and responding appropriately to governmental agencies and personnel; asserting civil and statutory rights through self-advocacy; building and maintaining interpersonal relationships; including a Circle of Support; participating in community life; and accessing emergency assistance, including the selection, installation, maintenance, repair, and training in the operation of, devices to facilitate immediate assistance when threats to the health, safety, and well-being occur.”

This is likely the most comprehensive definition of supported living services found in a waiver. It is written such that services can change *to meet the individual's evolving needs and preferences for support without having to move from the home of their choice*. This definition and the waiver, in general, allow the state to provide services not covered under the State Plan. For example, if the State Plan did not include personal care services, it is thought that the above definition would suffice to provide that support.

Utah

Community Living Supports serve the purpose of facilitating independence and promoting community integration by assisting an individual to gain or maintain skills necessary to live as independently as possible in the type of community-based housing arrangement the individual chooses, consistent with the outcome for community living defined in the individual's support plan.

Community Living Supports can include up to 24-hour direct care staff support. Actual type, frequency, and duration of direct care staff support, and other community living supports will be defined in the individual's support plan based on the individual's selected housing arrangement and assessed needs. Supports are available to individuals who live alone, with roommates, or with family.

Community Living Supports will include companion services, which consist of non-medical care, supervision, and socialization. Community Living Supports may also include direct support services that include assistance with meal preparation, eating, bathing, dressing, and/or personal hygiene.

Florida

Supported living means a category of individually determined services designed and coordinated in such a manner as to provide assistance to adult clients who require ongoing supports to live as independently as possible in their own homes, to be integrated into the community, and to participate in community life to the

fullest extent possible. This includes **supported living coaching** and other supports.

Supported living coaching are services that provide training and assistance in a variety of activities to support individuals who live in their own homes or apartments. This may include assistance with finding appropriate housing, the acquisition, retention or improvement of skills related to activities of daily living such as personal hygiene and grooming, household chores, meal preparation, shopping, personal finances and the social and adaptive skills necessary to enable individuals to reside on their own.

To Bundle Or Not to Bundle.

The main considerations around to “bundle or not bundle,” revolve around the current service delivery system configuration. When the state expects to buy supported living for a person from agencies that will provide or arrange for all the services and supports, bundling will simplify transactions and billing. The main challenge is accountability. As with any other ‘prospective’ system, it is necessary to check that the dollars provided to the agency were actually spent on services. Bundling does not make sense when the provision of supported living to a single person involves several different providers (e.g., personal assistance is provided by several workers each of whom is an independent contractor, or Agency A provides the personal assistance while Agency B provides skill training).

Individualized Budgets

Introduction.

The proposal requested a discussion of fair and practical methods and instruments to calculate individualized budgets based on individual need.

No One Answer.

There is no instrument that in and of itself can be employed to calculate an individual budget based on individual need. Fundamentally, however, there are three approaches:

- **Tiers/Grids.** Assessment information is used to assign people to funding tiers (levels). This is a rough and ready approach and most easily accomplished. Kansas uses funding tiers across its HCBS waiver program - people are assigned to those tiers based on scores from the Developmental Disabilities Profile (DDP). The tiers are not specific to supported living. People in each tier get the same amount of money regardless of where they live (on their own or a group home).

The Kansas approach creates a level playing field among community living arrangements. Kansas provides for exceptions to the tier amount in the case of people who need more supports.

Utah also operates a tier system that is based on the Inventory for Client and Agency Planning (ICAP). Tier funding levels are keyed to costs of conventional services (e.g., group homes, day program). Where alternate living arrangements are employed, the same amount of dollars is available.

- **Data Based/Data Driven Models.** Wyoming DOORS is an example of this approach. DOORS sets an overall budget allotment per person and it is not keyed to any particular living arrangement. The DOORS model is, therefore, seen as neutral as to living arrangement. It relies on ICAP data (ICAP variables are considered to be *proxy* descriptors of “need”).

Pennsylvania is developing a DOORS-like model but using a broader set of variables in its model. Pennsylvania is including some variables that are ICAP-like and some that describe other factors that affect cost. The aim in Pennsylvania also is to develop an overall individualized budget allocation amount for each person. Development of data-based/date-driven models is practical and feasible, but requires considerable work to implement.

- **Person-by-person with “Wiggle Room.”** The other approach is to simply build the budget person-by-person, but have “wiggle room” limits based on assessment data. In other words, the dollar allocation is not pre-set, but plans that exceed a certain limit must go through an exception process. The North Dakota system uses this approach. This type of limit and exception methodology may not be elegant in design, however, it is likely superior to inflexible limits methodology.

Answer to a Basic Question.

There is an underlying question that a State must answer before deciding whether or not to use an individualized budget methodology. The question is actually twofold: (1) does the State want to develop a “budget allocation” system that establishes an overall dollar amount for the total of all services received via the HCBS waiver program; or (2) does the State want to more narrowly focus on payment rates for a specific service such as supported living. If the former, then the DOORS system used in Wyoming would seem appropriate. If the latter, then likely the most practicable

and feasible approach is the use of limits and an exception process similar to the North Dakota approach. Such a methodology would enable individualized rates to be tied to a service plan using a standardized pricing method.

Wyoming “Doors” Development of Individualized Budgets¹³

Many states that are considering the development of a “budget allocation” for all services received via the HCBS waiver program and have expressed an interest in the Wyoming model. As mentioned above, Wyoming has established a method for determining individual budgets called DOORS. The primary goals of this individual budgeting methodology are to: (1) improve equity among waiver participants and; (2) increase the authority of the consumer’s service planning team.

Prior to 1998, the state used assessment information to divide individuals into one of five individual cost tiers. Under this methodology, individuals within the same funding tier could have large differences in needs. Consequently, a small change in needs measured by the assessment could lead to a large difference in an individual budget. As a result, stakeholders frequently complained to state staff or requested more funding.

Wyoming changed its method for determining individual budgets in 1998 to make funding levels more sensitive to individual needs and to reduce appeals of local service planning decisions. At that time, the state started to use a statistical analysis of state historical data on individuals’ needs and services to determine individual budgets. Each individual is provided with an individual budget, a maximum level of funding that varies for each consumer according to measures of his or her service needs. State staff has reported this method is widely regarded as fair by individuals with developmental disabilities, their families, and program providers.

¹³ Adapted from a CMS ‘best practices’ paper titled *Wyoming--Individual Budgets for Medicaid Waiver Services*.

Methodology for Computing Individual Budgets. The basic steps that the state uses in computing individual budgets are as follows:

1. State identifies factors that influence the level of support a person needs and are consistent with the state's policy that individual service costs should be independent of provider choice.
2. State data on these factors are included in a statistical analysis (stepwise multiple regression) to calculate individual budgets.
3. The calculation assigns weights to statistically significant factors in order to 'describe' the variance in individual budgets as much as possible.
4. The resulting formula (regression model) is the basis for determining individual budgets (in fact, there is one formula for adults and another for children).

Other Information. To assure the accuracy, consistency, and validity of assessments, Wyoming uses an independent private agency to complete them. This agency does not provide other services for people with developmental disabilities nor does it participate in local planning teams. In the last four years, the use of the DOORS system has produced a number of positive outcomes that include: fewer requests for additional funding; the amount of funding requested per person has decreased; and, a slower increase in cost per person.

The basic process is that: (1) individuals are assessed and if eligible for waiver services; (2) an individual budget is determined; (3) the budget is provide to the Individual Service Coordinator who facilitates the development of a service plan with the planning team; and (4) the plan includes a description of formal and informal services and supports, other payment sources, waiver services, providers, and

payment rates. There are methods for granting exceptions to an individual's budget limit. In fact, a portion of each waiver's overall state budget is set-aside for people who need more funding than is indicated by the individual budget formula.

System Architecture Supports Individual Budgets and Person-Centered Services.

The successful implementation of a supported living option depends on individualized, person-centered services. While most states would like to move towards person-centered services and supports, there is a growing recognition that present system 'architecture' (e.g., policies concerning service authorization, reimbursement, support coordination) stands squarely in the way. So, many states are beginning to implement a new service model (e.g., individual funding, individuals and their families have the authority in the selection of services and supports).

The success of the DOORS individual budget setting methodology in Wyoming is likely due in large part to what is referred to as the underlying system architecture.¹⁴

In fact, the State of Wyoming put into place a new architecture several years ago. The central features of Wyoming's system architecture that create a solid platform for the provision of person-centered supports are:

- a model way for making individual resource allocations on a person-by-person basis;
- clear assignment of the authority to make decisions about services to planning team that supports each individual;
- authority for individuals to select their own service coordinators;
- adherence to the principle that individuals and families have free choice of

¹⁴ Excerpted from Wyoming's Person-Centered System Architecture, by Gary Smith, National Association of State Directors of Developmental Disabilities, Inc. Special Projects (2001)

- service providers; and,
- policies that encourages new providers.

The DOORS System. As previously described, Wyoming has developed and implemented a system for assigning a unique Individual Resource Allocation (IRA) to each individual who participates in the state's Medicaid home and community-based waiver. Each planning team knows when how many dollars are available to obtain services and supports and has the authority to allocated resources in a way that best meets the needs of the individual. Wyoming stakeholders regard the DOORS IRAs as fair because money is assigned even-handedly to each individual by taking into account exactly the same factors.

Planning Teams Are In Charge. Wyoming empowers each individual's planning teams to make decisions concerning services and supports. Planning teams may select services and supports from the HCB waiver program's menu, determine their mix and volume, and select the providers to supply the services and supports. Person-centered planning is in wide use in Wyoming. The state requires that the plan be person-centered - that is, it reflect the needs and preferences of individuals and spell out how they will be met.

Individuals Select Their Own Service Coordinators. During the mid-1990s, Wyoming implemented a policy that authorizes individuals and families to freely select any qualified service coordinator. Service coordinators may be employees of provider agencies or they may be independent contractors. All service coordinators must meet the same set of qualifications. Payment rates for service coordination are the same regardless of the service coordinator selected by the individual or family.

Free Choice of Providers. Federal Medicaid law provides that each individual freely may select any qualified provider to provide an authorized service. More broadly, free selection of providers is absolutely central to person-centered supports. Individuals

and families not only must be able to exercise choice in the selection of services and supports but also their source. In many states, free choice of provider often is honored more in concept than practice. A few years ago, the Division of Developmental Disabilities terminated "state contracts" for adult services. These contracts were viewed as "provider-based." As a result, persons served were not truly free to choose a provider.

Expanding Providers. The principle that individuals must have the authority to choose their service provider(s) is undermined when there are only a limited number of providers. This is especially true in low population-density states such as Wyoming (and Idaho). Wyoming has addressed this challenge through: (1) its adherence to individual and family free choice of provider; (2) the policy that funding is portable across services and provider agencies; and (3) streamlined procedures that enable individuals to sign up and be approved as service providers. There literally are hundreds of providers of HCB waiver services in Wyoming. The State's capability to contract quickly means that the state has not to develop "financial intermediaries" or special contracting procedures in order to work around policies that stand in the way of contracting only with licensed agencies.

Self-Determination and Supported Living Services

Introduction.

The Council also asked how self-determination principles are incorporated into supported living.

A Brief Overview of Self-Determination.

In a recently developed protocol for waiver audits, CMS recommends that auditors look for evidence that providers *foster waiver participant self-direction and self-determination and promote waiver participant independence and dignity.*

Self-determination is a set of principles that support self-direction and independence for people with developmental disabilities. The four basic principles (excerpted from Robert Wood Johnson Foundation, 1998) are as follows:

- **Freedom.** Individuals (with assistance when necessary) establish where they want to live, with whom they want to live and how their time will be occupied.
- **Authority.** Individuals control the financial resources needed for support through the development of an individual budget.
- **Support.** The individual determines the amount and timing of services and supports and who provides them.
- **Responsibility.** The wise use of public dollars and the ordinary obligations of American citizens to contribute to their communities in meaningful ways.

Emerging Best Practices in Self-Determination.¹⁵

There are three practices that are emerging as the major innovations in self-determination:

Individual Budgets. The person with a disability and chosen family and friends create the individual budget. Any person who works for the individual is hired and can be fired by him or her as well. In fact, all employees and consultants work for the person and that person's social support network. Within approved amounts, dollars can be reasonably moved from line item to line item as long as the essential supports are maintained. New line items may also be created as well as old ones erased.

Independent Support Coordination. A key to the successful implementation of individual budgets is the independent support coordinator, personal agent, or independent broker. This is a person selected by the individual (with support from family and friends as needed) who may help with plan development, assist in organizing the resources that a person needs and even assist with ongoing evaluation of these supports. There are many ways that this function can be carried out by family members or case managers assuming new roles. It is important to keep this function separate from any form of service provision in order to avoid both the appearance and the reality of conflict of interest.

Fiscal Intermediaries. The functions carried out by a fiscal intermediary include, but are not limited to, check writing for bills and personnel costs, tax withholding, paying worker's compensation, health insurance and other taxes and benefits depending on the individual's budget. The fiscal intermediary works for the individual and remains accountable for insuring compliance with all federal and state laws. Fiscal intermediaries are independent of service provision.

¹⁵ Adapted from *Communicating Self-Determination: Freedom, Authority, Support and Responsibility* by Thomas Nerney, Center for Self-Determination (2002).

Self-Determination and Supported Living.

Self-determination concepts and practices cover all services. Supported living services and self-determination are a good fit. In fact, the test for one can be used for the other as well. We can be fairly certain that both supported living and self-determination practices are in play if the individual with support from family and friends as needed chooses: (1) where to live; (2) with whom to live; (3) individuals or agencies who provide services; (4) when and how services are provided. To further support self-determination within supported living, individuals would have control over the use of resources through an individual budget.

While some initial concerns have been expressed, the Independence Plus waiver templates recently developed for states by CMS will support additional opportunities for both self-determination and supported living. The templates provide the *tools to create programs that allow people with disabilities and their families to decide how best to plan, obtain and sustain community-based services, placing control into the hands of the people using the services.* California is currently developing an Independence Plus waiver to continue the development of their self-determination pilot across five regional centers.

Moving toward Self-Directed Services.

Shifting a state developmental services system to an individual and/or family determined approach from a program-based approach is formidable. The State of Kentucky is considering ways to make that shift. In so doing, they conducted a study on the readiness of providers to make that shift under their Supports for Community Living waiver¹⁶. The study included visits to twenty-five agencies that provide community living services (e.g., group to supported living, workshop to supported

¹⁶ Adapted from a *Summary Of Kentucky Readiness Review Report* (2001), prepared by Mercer Incorporated.

employment) of all kinds. The study provided the following observations and recommendations (relevant to other States as well) as important elements in a transition to self-determination:

- Agencies that focus on supported living and employment will face fewer challenges in making the conversion.
- Funding and services must be directly tied to the plan in order for the implementation of person-centered supports.
- Independent support coordination is necessary to reduce the conflict of interest of agency support coordination.
- At this time, person-centered plans are limited to what services are offered by the agency.
- A system of fiscal intermediary services needs to be developed.
- Service rates need to be recalculated based on a consistent rate methodology and to be "portable."
- A database for tracking provider capacity and expenditures must be developed.
- A person-centered 'architecture' (e.g. state policies, training, person-centered planning, individualized budgeting) must be developed prior to implementation.

Risk Management and Liability

Introduction.

Another issue for the Council is how basic risk management and liability issues are handled in supported living.

Basic Concepts.

Risk management starts with solid risk assessment to identify what the risks are and how they will be addressed. Solid risk assessment and acting on the results of the assessment are the main ways to address potential liability issues (i.e., asking what can go wrong and what needs to be in place in case it does). The more general topic of "liability" is more complex.

The perceived liability in supported living is thought to be vastly greater than the reality. In most cases, it revolves around the ongoing "risk versus independence" issue. One emerging method of tackling some forms of potential liability is what are labeled "informed consent contracts." These are used when a person refuses a safeguard even though the provider believes the safeguard is necessary. An informed consent contract is a way to document that a person has refused a safeguard after fully being informed of the potential consequences. It is not clear that such devices will hold up, especially in the case of individuals with cognitive disabilities.

It's relatively certain that liability cannot be extinguished completely regardless of the living arrangement. At the end of the day, liability is a problem to the extent that obvious risks have not been recognized and addressed. It follows that a solid system of risk assessment is the best approach to reducing risk and liability.

Risk Assessment on an Agency Level ¹⁷.

One of the serious challenges that supported living agencies face each day is supporting individuals who make risky decisions about their health and safety. Supported living agencies struggle with the tension that comes from supporting and encouraging individuals to both make their own choices and to live a healthy and safe lifestyle.

Supported living agencies work hard to have a partnership with the individual and a relationship based on mutual respect and trust. They recognize their obligation to try whatever they can to help people make fully informed decisions. It is not appropriate to shrug off responsibility with the justification that “people learn from their mistakes” because not everyone does. Nor is it appropriate to say that there is “dignity in risk taking”. There is no dignity in experiencing pain or tragedy.

Supported living agencies work collaboratively with the individual and their family and friends. They rarely terminate services to people even when supporting them becomes a challenge. Only when an individual is engaging in acts that are seriously jeopardizing their safety and health or the safety of others and the individual is unwilling to accept support and intervention services, would most supported living agencies consider ending services.

Options in Community Living of Madison, Wisconsin, have been providing supported living services since 1974. Early in their agency history, they developed a series of questions that they ask themselves when considering additional support for people who are placing themselves at risk. Any of the Options staff can convene an ‘at Risk’ meeting whenever it is felt that someone they support is at risk in any quality of life

¹⁷ Adapted from *Supported Living Services Training Tool Box*, California Department of Developmental Services by Bolton and Allen (2001).

areas (autonomy and choice, personal income, housing, physical and mental health, safety appearance and hygiene, relationships, meaningful activities, and mobility) or there's a drastic change in lifestyle or there is feedback from community members or the person's family that indicate a concern for well-being, safety or health. The following considerations are addressed to determine whether more staff support is justified:

1. What is the person's history of decision-making? (for example, previous experience or practice in exercising autonomy and rights, ability to learn from the natural consequences of poor decision-making)
2. What are the possible long and short-term consequences associated with poor decision-making? (What is the worst that could happen, for example, death, exploitation, illness, injury, isolation, rejection by others, involvement with law, substandard living conditions, or financial difficulties.)
3. What are the possible long and short-term consequences of increased support and direction by staff or system? (For example, decreased confidence or self-esteem, likelihood of increased dependence on staff, improvement in person's quality of life, possibility of person refusing to work with the agency.)
4. What are the trade-offs of continuing the current situation?
5. What are the safeguards to protect person's rights? (For example, individual assertiveness, availability of an advocate, friend, conservator, or guardian.)
6. Should more control and direction be provided?

Risk Assessment on a State Level.

The Department of Mental Retardation (DMR) in Massachusetts has developed a statewide approach to this issue with the development of the Risk Management System (RMS)¹⁸. The purpose of the system is to meet the challenge of balancing the health and safety of individuals with mental retardation with independence and self-determination. This system covers all types of living arrangements from group to supported living.

The RMS is designed to: (1) promote locally driven efforts; (2) foster partnerships among all stakeholders; and (3) support local efforts to keep people safe while promoting personal autonomy. It is also designed to provide the necessary level of administrative structure and oversight. The guiding principles of the RMS are:

- an emphasis on safeguards and strategies that address issues and create situations where risk is reasonable;
- a respectful process of identifying and addressing unreasonable risk while addressing questions of competency and capacity to make choices;
- the involvement of those who know an individual best in determining who is at risk;
- consideration of cultural and linguistic issues;
- integrated into the Individual Service Plan process; and
- locally based and implemented by individuals trained, supervised and

¹⁸ Excerpted from the online description of the Risk Management System provided by the Massachusetts DMR.

supported in making knowledgeable decisions through a collaborative group process.

The RMS has four basic components:

- **Risk Identification and Prevention.** A review process conducted by service coordinators.
- **Risk Assessment and Planning.** Persons determined to be at-risk will have a risk management planning meeting with their planning team.
- **Risk Training, Consultation, and Support.** Training for DMR staff working with person at-risk; also provider training and public education efforts.
- **Risk Management System Oversight Activities.** A standardized process coordinated by the Central Office Risk Management Director.

Negotiated Risk.

Earlier in this section, there was mention of an informed consent contract whereby an individual signs a statement that documents that he or she has refused a service after fully being informed of the potential consequences. The Franklin Pierce Law Center of Concord, New Hampshire, is working on another way to document risk and liability called 'negotiated risk.'

In their proposed study of the issue, they mention that providers (or members of a planning team or circle of support) may be reluctant to honor individual decisions when there is a fear that a particular decision will result in injury to the individual or another (and could also result in litigation). They further suggest that Medicaid regulations may, in fact, be in conflict with individual decision-making.

They intend to research: (1) New Hampshire law and statutes regarding the potential liability if an individual selects services and support that are not thought to provide adequate protections of health and safety; (2) Medicaid section 1915c waiver regulations regarding state and provider responsibility and to determine if it may be waived to support self-determination; and (3) the implications of self-determination, if any, for a service provider's liability policy coverage. The resulting publication (which will likely have implications for self-determination and supported living nationwide) will include recommendations on how liability can be allocated between service providers and individuals in order to promote self-determination.

Quality Assurance

Introduction.

We were asked to identify examples of good systems of quality assurance, and abuse and neglect protections for supported living.

Quality Assurance, Then and Now¹⁹.

Historically, quality assurance methods have involved certification, licensure, accreditation, or a combination. However, organizations and government agencies have begun to rethink the purpose and process of quality assurance. At least three shifts or trends are 'driving' this reevaluation: (1) a focus on quality enhancement rather than quality assurance; (2) a focus of best practices on the strengths and capacities of a service agency; and, (3) a move towards the development of partnerships with families, professionals, and communities.

A View from the Top.

In the *HCBS Primer* (2000), the Office of Disability, Aging, and Long-Term Care Policy noted that:

Community living presents a different set of risks from those associated with living in an institution. Transition programs need to have a quality assurance (QA) system that monitors and helps ensure service quality and client safety, particularly for the first few months in the community setting. At the same time, however, such a QA system must respect individuals' autonomy by acknowledging their choice to assume risk. The balance is delicate and can be hard to achieve.

¹⁹ Adapted from material presented in *Quality of Life and Quality Assurance* by Robert Schalock in *Quality of Life in Health Promotion and Rehabilitation* (Sage, 1996), edited by Rebecca Renwick, Ivan Brown and Mark Nagler.

Basic System Characteristics.

Quality assurance, quality management and safeguard systems are multi-dimensional topics and are not directly tied to any particular service type. The major difference between supported living and most other living arrangements in regards quality assurance is the absence of mandated monitoring via licensing agencies.

Whether supported living or another developmental service, there are some basic characteristics of a 'good' quality assurance system:

- Service coordinators who work with individuals in supported living must have reasonable work assignments. Highly customized services across scattered sites require lower workloads.
- A state must have an effective and functioning incident management system that includes mandatory reporting of abuse and neglect. It must also have developed clear lines of responsibility for follow-up and resolution once reports are received.
- Provider quality reviews need to be thorough and frequent.
- Individuals and families should be able to register complaints or express concerns to an independent entity that has authority to conduct fact-finding and seek resolution of problems.
- There must be a strong focus and ongoing commitment to direct support professional training and education.

In addition to the above elements, states that have had some success in developing innovative quality assurance systems often have a complementary system of

independent quality review teams (composed of peer providers, family members, people with disabilities, and advocates). These teams focus on assuring quality at the level of the individual.

A System and Statewide Approach.

The state of Kansas has developed a quality assurance system for individuals who use waiver services that centers on the individual regardless of living arrangement.²⁰

There are three basic features of the system: 1) the Kansas Lifestyle Outcomes (KLO); 2) Quality Enhancement Coordinators; and 3) local quality enhancement teams.

Those features are briefly described below:

Kansas Lifestyle Outcomes. The KLO was designed as a way to measure the presence or absence of various outcomes in a person's life. There are two groups of lifestyle outcomes. The first group focuses on indicators that relate to standards of care (e.g., the presence of a person-centered plan, safe and healthy environments, opportunities for valued day activities, appropriate administration of medications). The second group of the outcomes focuses a person's preferred lifestyle (e.g., choice of living and employment, satisfaction with day activity, choice of social activities). A Quality Enhancement Coordinator administers the KLO to a random sample of individuals using the services of each agency. In addition, the KLO is completed with any individual for whom a family or community member has reported that they have a concern regarding services. These visits are almost always unannounced.

Quality Enhancement Coordinators (QEC). The QEC is responsible for licensing new provider and for following-up on all abuse and neglect reports. The QEC is also responsible for ensuring that the providers are in compliance with regulations.

²⁰ Adapted from *A Review of the Medicaid Home and Community-Based Services for Adults with MR/DD in Kansas* from the Lewin Group for CMS (2000).

When an issue arises, the QEC typically alerts the appropriate staff within the agency and requests a correction plan if necessary. The QEC also provides technical support to Community Developmental Disability Organizations (CDDOs) and independent agencies on regulations, person-centered planning, rights, abuse/neglect and other topics as needed.

Local Quality Enhancement Teams. Each CDDO is required to have a quality assurance (QA) committee comprised of volunteer members. By statute, 50% of the committee members must be family or individuals with developmental disabilities. The QA committee follows-up on all incident and accident reports as well as reports of abuse or neglect. They typically review the KLO surveys completed by the QEC and in some cases, they may complete the KLO surveys.

Other Elements. The state has a registry of individuals who are “confirmed” to have been perpetrators of abuse or neglect to people with developmental disabilities. Once an individual is placed on this registry, he or she is no longer allowed to work in the field of developmental disabilities. In addition, almost all agencies conduct a “risk assessment” during support team meetings to determine the balance between protection from harm and the right to take risks.

Children's Waivers

Introduction.

The project called for some research into States that have a children's waiver and the feasibility of amending the Idaho State School and Hospital HCBS waiver to include children (discussed in a later section).

Olmstead Planning Group.

This request may have been the result of one of the findings of the group that there is currently *an inadequate array of services for children* and the recommendation to *explore an HCBS waiver for children*. The group also indicated that current services for children in Idaho are limited to those available through the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program. Also, that services under EPSDT do not fund out-of-home placements, except for children who qualify for 24-hour personal care services (PCS). It is further suggested that Medicaid funds could be used for family support services and that the non-availability of these services in Idaho results in families seeking placements at ISSH or other ICFs/MR.

Basic Types of Waivers for Children.

There are a few states that operate waiver programs that serve only children. There are more states that operate HCBS waiver programs that serve both children and adults in the same program. HCBS waiver programs for children with disabilities are of three types:

- Programs that offer relatively comprehensive services and, thus, are able to meet the needs of children who have fairly intensive support needs. Five of states are in this category. The Children's Waiver in Wyoming was initiated as

a result of a consent decree. However, it has since grown into a relatively large program (520 children as of 11/05/02). Nebraska also has a children's waiver program. It is smaller than Wyoming's program, but it is also relatively full featured. Since 1985, New Mexico has operated an HCBS waiver program for children who have intensive medical needs. Unlike the Nebraska and Wyoming waiver programs, this one does not provide for services outside the family home. Michigan also has a waiver program for children with intensive needs as does Alaska.

- A few states have started up "family support" waiver programs. These offer a dollar limited package of benefits for children who live with their families. There are programs using this approach in Oklahoma and Louisiana.

- Finally, there are a few states that operate so-called "model waiver" programs for children. The main purpose of these programs is to connect children who live in higher income households to Medicaid services. The waiver itself might offer limited benefits (e.g., case management, respite.) However, children on these programs can also access the full range of Medicaid benefits via EPSDT. States that have programs such as this include New York, Missouri, and Connecticut.

Example of a Comprehensive Children's Waiver²¹.

The Children's Home and Community-Based Waiver in Wyoming is a Department of Health program that allows eligible children to receive services not covered by the regular state Medicaid plan. Children eligible for waiver services are aged birth through 20 years, mentally retarded or have a related condition that requires active treatment at the level of care of an Intermediate Care Facility for the Mentally

²¹ Adapted from public information regarding from the Wyoming Developmental Disabilities Division (2002).

Retarded (ICF/MR). The goal of the waiver is to provide home and community-based services that enable the child to stay in the local community rather than being institutionalized. The intent is to relieve pressures on families by assisting them in meeting the needs of their developmentally disabled child. The range of services available for children are summarized below:

Case Management. Services that will assist waiver recipients in gaining access to needed services, regardless of the funding sources.

Homemaker. General household activities when the individual regularly responsible is temporarily absent or unable to provide caregiving.

Respite Care. Services provided on a short-term basis because of the absence or need for relief of those persons normally providing the care.

Residential Habilitation. Assistance with skills related to activities of daily living, and the social and adaptive skills necessary to enable individuals from eighteen through twenty years of age to reside in a community-integrated setting.

Supported Habilitation Training. Designed to assist eighteen through twenty year olds in acquiring the self-help and adaptive skills necessary to reside successfully in a home and community based setting, such as an apartment.

Special Family Habilitation Home with and without Transportation. Services designed to allow individuals to acquire self-help, socialization and adaptive skills necessary to reside in the home of an adult other than the natural or adoptive parent. Depending on the service, transportation is provided by the provider or someone other than the provider.

Residential Habilitation Trainer with or without Transportation. Services include training and/or assistance to address basic skill needs either in the home of the child's natural or adoptive parents, in a Special Family Habilitation Home or in Supported Habilitation Training. Depending on the service, transportation is provided by the provider or someone other than the provider.

Environmental Modifications (New and Existing). Initial and ongoing physical adaptations to a home that enable an individual to function with greater independence.

Skilled Nursing. Services provided by a registered professional nurse, or licensed practical or vocational nurse under the supervision of a registered nurse.

Specialized Equipment and Supplies (New and Existing). Specialized medical equipment and supplies that enable individuals to perform activities of daily living or communicate (also includes maintenance and durable and non-durable medical equipment not available under the Medicaid State Plan).

Respiratory Therapy. Provided under the prescription of a physician.

Psychological. Services include individual and group therapy, consultation, development and monitoring of behavior programs; participation in the individual planning process; and counseling for primary caregivers.

Dietitian Services. Provided by a registered dietitian and includes meal planning, consultation and training for caregivers, and education for the individual.

Special Diets. Physician prescribed nourishment, which are necessary for the individual to maintain and/or improve optimal health.

Personal Care. Includes assistance with eating, bathing, dressing, personal hygiene, activities of daily living, and supervision. Personal care providers may be members of the individual's family, but payment cannot be made to parents or step-parent for services furnished to their minor child.

Example of a Waiver for Children²² who are Medically Fragile.

As previously stated, the waiver program for children in New Mexico was originally approved in 1985. (Note: The program was originally designed to serve children to the age of twenty-one, but is currently able to serve adults who meet eligibility requirements as well.) It is intended for individuals who have been determined to be both medically fragile and developmentally disabled, developmentally delayed or at risk for developmental delay.

Medically fragile is defined as a chronic physical condition that results in a prolonged dependency on medical care that requires daily skilled nursing intervention. An individual must meet both medical and financial eligibility requirements (the same criteria required for institutional care). The program allows for only the child's income and resources to be counted.

²² Adapted from public information from New Mexico Department of Health Services.

The waiver program works with a statewide, contracted case management agency to coordinate a family-centered approach to providing services. The case manager, direct service providers and families develop the service plan in conjunction with the individual's primary care physician. The program provides in-home services that support the family in providing care for their family member at home. Services for eligible individuals include: case management (Registered Nurses only); private duty nursing (RN & LPN); home health aide; physical therapy; speech therapy; occupational therapy; psychosocial counseling; nutritional counseling; and respite.

Amending the ISSH Waiver to Include Children.

One waiver specialist suggests that the major issue in serving children via the HCBS waiver program is the need to coordinate waiver benefits and Medicaid state plan benefits. For example, in conjunction with the EPSDT program. Since children are able to access any potentially coverable service via EPSDT, waiver benefit packages for them are generally more narrowly defined than for adults. From a coverage standpoint, the ISSH waiver may need to be reviewed in order to include different types of providers and services than at present (e.g., foster care). Fundamentally, the main issues are likely internal and not federal. If children are placed out of ISSH, where will the placements be made, is the present waiver configured appropriately to cover the necessary services, and do any special accommodations need to be made vis-à-vis the generic child welfare system?

Community Transition Services

Introduction.

We were asked to discuss the benefits and limitations of adding community transition services to Idaho's HCBS menu of waiver-funded services.

Past Use.

For several years, CMS has supported the transition of individuals who are seniors and/or have physical disabilities. In a letter clarification to the States, the CMS Director recently noted that “. . . states may pay the reasonable costs²³ of *community transition services*, including some or all of the following components:

- security deposits that are required to obtain a lease on an apartment or home;
- essential furnishings and moving expenses required to occupy and use a community domicile;
- set-up fees or deposits for utility or service access (e.g. telephone, electricity, heating);
- health and safety assurances, such as pest eradication, allergen control or one-time cleaning prior to occupancy.”

²³ Reasonable costs mean necessary expenses in the judgment of the state for an individual to establish his or her basic living arrangement. States that choose to include community transition services in their HCBS waivers must demonstrate that this service, in combination with other services furnished under the waiver, would be cost-neutral to the Medicaid program.

Example of a Typical Community Transition Services²⁴.

Through a grant from CMS, Maryland has developed a transition program for people with physical disabilities living in nursing homes. A transition specialist meets with eligible individuals (and their families and friends) who want to move. The primary service includes education about living options and providing information about affordable and accessible housing and local community support resources. In addition, transition specialists have access to funds for assisting individuals with security and utility deposits, environmental modifications, and obtaining necessary furnishings.

New Opportunities²⁵.

In the past year or so, CMS has identified some opportunities for states to obtain Medicaid reimbursement for some services provided on behalf of individuals with developmental disabilities who are current residents of ICFs/MR and nursing facilities and who are transitioning to the community. Those transition services are somewhat more limited than the services mentioned above, however, they include:

Service coordination. There are several ways that case management services may be furnished under the Medicaid program. First, targeted case management may be provided during the last 180 consecutive days prior to transition. In addition, HCBS case management can be provided for up to 180 consecutive days as well, however, it cannot be claimed until the individual actually leaves the institution and is enrolled in the waiver. The third option is known as administrative case management and covers activities needed for the establishment and coordination of Medicaid services that are not services funded by other payors for which the individual may qualify.

²⁴ Adapted from materials provided by the Centers for Medicare and Medicaid Services (2002).

²⁵ Adapted from materials provided by the Centers for Medicare and Medicaid Services (2002).

Assessments for accessibility. State may claim for the assessment of accessibility and need for modification in a individual's prospective home or vehicle. There are several ways to claim for this service (e.g., administrative expense, included in the cost for environmental modifications, as a relevant service).

Environmental Modifications. A State may claim for home modifications (including actual construction costs) furnished as a waiver service for up to 180 days prior to transition. The modifications can be initiated before the individual enrolls in HCBS waiver, however, home modifications must be included in the approved waiver.

Use of Service.

Although limited in scope, it appears that transitional services could be a positive addition to a state waiver. For example, it would support the considerable cost of coordinating the team, developing the transition plan and lining up needed community services and supports.

Challenges for Increasing the Use of Waiver-Funded Supported Living Services in Idaho

Introduction.

The authors of this report were contracted to look at the challenges of waiver-funded supported living services in Idaho and to present considerations for change. This section of the document offers a summary of those challenges. It is based on observations of the authors as well as a review of materials and the thoughts and perceptions of the Idahoans that we interviewed and e-mailed. The next chapter includes considerations for changes in the waiver as well as state policy and practices.

A Summary of Challenges.

The Centers for Medicare and Medicaid Services are sponsoring several initiatives focused on quality management and improvement in home and community-based services. One such initiative is the CMS Quality Framework²⁶. The Framework focuses attention on desired outcomes. It identifies seven broad quality domains and associated sub-domains with outcomes for each (see the following page). It will initially be used as a self-assessment among the States. A 'report card' summary across all states will be developed from the responses.

The following pages include an overview of the major domains of the Framework as well as a 'simulated' assessment of the challenges to and considerations for increasing the use of waiver-funded supported living services in Idaho. For the purposes of this report, we have provided 'discovery' elements that indicate only challenges. Considerations for change will be presented in greater detail (e.g., cost

²⁶ Excerpted from the National Quality Inventory Project (2002).

implications) in the next section of this document.

HCBS Framework Domains and Associated Sub-Domains

| Domain | Associated Sub-domains |
|---|---|
| I. Participant access | <ul style="list-style-type: none"> A. Information/referral B. Intake and Eligibility <ul style="list-style-type: none"> 1. User-friendly processes 2. Eligibility determination 3. Referral to community resources 4. Individual choice of HCBS 5. Prompt initiation |
| II. Participant-centered service planning and delivery | <ul style="list-style-type: none"> A. Participant-centered service planning <ul style="list-style-type: none"> 1. Assessment 2. Participant decision making 3. Free choice of providers 4. Service plan 5. Participant direction B. Service delivery <ul style="list-style-type: none"> 1. Ongoing service and support coordination 2. Service provision 3. Ongoing monitoring 4. Responsiveness to changing needs |
| III. Provider capacity and capabilities | <ul style="list-style-type: none"> A. Provider networks and availability B. Provider qualifications C. Provider performance |
| IV. Participant safeguards | <ul style="list-style-type: none"> A. Risk and safety planning B. Critical incident management C. Housing and environment D. Behavior interventions E. Medication management F. Natural disasters and other public emergencies |
| V. Participant rights and responsibilities | <ul style="list-style-type: none"> A. Civic and human rights B. Participant decision making authority C. Alternate decision making D. Due process E. Grievances |
| VI. Participant outcomes and satisfaction | <ul style="list-style-type: none"> A. Participant satisfaction B. Participant outcomes |
| VII. System performance | <ul style="list-style-type: none"> A. System performance appraisal B. Quality improvement C. Cultural competency D. Participant and stakeholder involvement E. Financial integrity |

**Home and Community-Based Services (HCBS) Quality Framework
 Simulated Review of Challenges to Waiver-Funded Supported Living Services in Idaho**

| | Design | Challenges |
|---|--|--|
| Domains | | |
| Participant Access | Desired Outcome: Individuals have ready access to home and community-based services and supports in their communities. | In several regions of the state and in many large towns (e.g., Idaho Falls), there are few or no available supported living services. |
| Participant-Centered Service Planning and Delivery | Desired Outcome: Services and supports are planned and effectively implemented in accordance with each participant's unique needs, expressed preferences and decisions concerning his/her life in the community | There are no provisions in the current rate structure to support assessment and planning for individual needs. Person-centered planning has been unevenly implemented. As a result, service providers often receive little or no information on how to successfully support an individual referred for services. |
| Provider Capacity and Capabilities | Desired Outcome: There are sufficient HCBS providers and they possess and demonstrate the capability to effectively serve participants. | There are currently three agencies providing services to 85% of all individuals using supported living. |
| Participant Safeguards | Desired Outcome: Participants are safe and secure in their homes and communities, taking into account their informed and expressed choices. | It appears that some State staff have concerns about health and safety as individuals in supported living environments are not monitored in the usual way (e.g., licensing and certification). |

Idaho Council's Supported Living Project

| | Design | Challenges |
|--|---|--|
| Domains | | |
| Participant Rights and Responsibilities | Desired Outcome: Participants receive support to exercise their rights and in accepting personal responsibilities. | When several of the key tenets of supported living (choosing where and with whom to live, what to do during the day) is not typically in evidence, it is difficult to further assess this outcome. |
| Participant Outcomes and Satisfaction | Desired Outcome: Participants are satisfied with their services and achieve desired outcomes. | This outcome is not currently being assessed. However, it is known that some individuals have left the service because of the restrictive nature of developmental therapy 'programming.' |
| System Performance | Desired Outcome: The system supports participants efficiently and effectively and constantly strives to improve quality. | There are as many as three audits per year of supported living service agencies depending on the 'bundle' of services provide (e.g., residential habilitation, behavioral consultation, adult day care, and developmental therapy under the Regular Medicaid Waiver). These audits appear to be basically fiscal in nature and not typically programmatic. |

What We Learned About How Supported Living Services are Perceived.

When asked to describe supported living services, the Idahoans we talked to expressed a number of different views. For example, a service coordinator stated that supported living is a service right after ICFs/MR on the continuum of living arrangements in Idaho. A staff member of a supported living agency mentioned how people 'graduate' from supported living. Others (e.g., State and supported living agency staff) referenced supported living as a service arrangement where two people live together and get twenty-four hour, seven day a week staff support.

One thing that we learned from all of the interviews and materials we reviewed is that supported living in Idaho does seem to meet the basic criteria of supported living as it is typically defined. Individuals seem to have their name on a leases or rental agreement, however, that appears to be where the similarity ends. Individuals do not typically choose where to live or with whom they live. In addition, they do not typically have the freedom to choose what they do during a significant part of the day. The supported living 'package' often includes a structured four to six hours a day of developmental therapy. While we were not asked to interview individuals in supported living, the few we happened to talk to were not fond of that arrangement. In fact, one individual stated that it interfered with her 'having a life.'

We will describe what we learned about how this 'package' was developed later in this section. While we do not think supported living services as currently provided in Idaho meet some basic 'tests', we are certainly not suggesting that the services are not good ones or that they are not needed. In fact, we learned that one of the few things that all (e.g., supported living providers, state agency staff and advocates) agree on is that supported living services (as currently provided) have been an invaluable element in transitioning individuals from ISSH to the community.

What We Learned About Individuals Who Use the Services.

We learned that Individuals who use waiver-funded supported living services in Idaho most typically:

- require 24-hours a day, seven days a week support;
- have behavioral, mental health, or medical challenges; and
- live with one or more housemates whether or not they choose.

There are, apparently, some individuals who do not require 24-hour support and who live in their own homes. They are often supported through *residential habilitation* services offered as a part of the HCBS waiver or by *personal care services* provided through the A & D waiver. Most of the individuals we interviewed suggest that these individuals have strong natural support systems (e.g., family members who provide care or financial resources).

What We Learned About the Availability of Services.

In the developmental services system as in any other 'service' sector, rates of pay or reimbursement influence the availability of services. In regards availability, the CMS (2000) states that *State payment levels must be high enough to attract sufficient providers to meet the needs of beneficiaries*. The availability of supported living services in Idaho appears to be limited by the type of disability (e.g., significant behavioral challenges), geography and providers willing to offer the service. At this time, three agencies provide waiver-funded supported living services to the vast majority of individuals who use the service.

We mentioned above a description of the narrow range of individuals who typically use supported living services. In addition, there appear to be definite geographic limitations to the service. While this is certainly understandable in very rural areas of the state, this geographic limitation includes larger urban areas as well. For example, a local service provider mentioned that there were no supported living services in Idaho Falls. The information below appears to substantiate that statement.

**Expenditures for Waiver-Funded Supported Living Services
by Region for June, 2002**

| Region | In own home | Shares with 1 other | Shares with 2 others | Totals |
|---------------|--------------------|----------------------------|-----------------------------|-------------------|
| 1 | \$ 15,703 | \$ 86,340 | \$ 3,961 | \$ 106,004 |
| 2 | \$ 41,130 | \$ 58,128 | \$ 3,102 | \$ 102,360 |
| 3 | \$ 22,769 | \$ 10,858 | \$ 4,070 | \$ 37,696 |
| 4 | \$ 22,387 | \$ 186,894 | \$ 48,178 | \$ 257,458 |
| 5 | \$ 15,469 | \$ 75,691 | \$ 7,509 | \$ 98,669 |
| 6 | \$ 12,812 | \$ 14,871 | \$ 4,030 | \$ 31,713 |
| 7 | \$ 1,155 | \$ - | \$ - | \$ 1,155 |
| Totals | \$ 131,425 | \$ 432,781 | \$ 70,850 | \$ 635,056 |

For comparison, in the city of Napa (California), a town of similar size to Idaho Falls there are currently about 100 individuals using supported living services provided by four agencies. To further draw the comparison of differences regarding the availability of the service and persons served, we provide some additional information about one supported living agency in Napa.

The agency provides supported living services to eighteen individuals who use from 10 hours per week to 24 hours a day (eight of eighteen) of service. Some individuals attend day programs or school during the week, while others work or volunteer. Some individuals have behavioral challenges, others have physical in addition to developmental disabilities. Eleven of the eighteen live by themselves or with a paid

or non-paid roommate. Seven of the individuals have roommates with disabilities who do not use supported living services.

What We Learned a About Person-Centered Planning.

In terms of planning for supported living services, some state agency staff, advocates, providers and service coordinators hold the view that: (1) not all services coordinators are good at person-centered planning; and (2) the current, one-time rate for assessment is not adequate to develop an thorough, person-centered plan. In addition, this typically means that the task of designing a personalized support plan falls to the supported living service provider.

Since there is no reimbursement for initial assessment, agencies either: (1) learn as they go about the people they serve; or (2) spend the time up front to develop a support plan at their own cost. While agencies always learn more about individuals as they support them, lack of information up front leads to a variety of risky conditions for both the individual served and the agency (e.g., unknown methods of working with challenging behaviors, poor matches with housemates or staff).

In order to get a better idea of the types of plans that are developed for supported living services, we requested four representative plans. We used a set of criteria for determining the presence or absence of the basic elements in a person-centered plan. As indicated on the following matrix, the plans did not fair well when using that criteria.

Review of Four Plans for Individuals Using Supported Living Services

| Indicators of Person-Centered Planning | Plan 1 | Plan 2 | Plan 3 | Plan 4 | Percent of Total |
|---|------------|------------|------------|-----------|------------------|
| The plan describes what others like and admire about the individual. | No | No | No | No | 0% |
| The plan describes what is important to the person and what needs to be present to live a preferred lifestyle based on what the person says or communicates through behavior. (Included is information about important relationships, activities, and places and important routines that need to be supported.) | No | Yes | Yes | No | 50% |
| The plan describes what is important for the person in terms of staying healthy and safe. | No | No | Yes | No | 25% |
| It outlines what others need to know and do to support the person in living a preferred lifestyle and staying healthy and safe. | No | No | No | No | 0% |
| The plan outlines what is working to support the person and needs to stay the same. | Yes | Yes | No | No | 50% |
| The plan outlines what is not working to support the person and needs to change. | No | Yes | Yes | No | 50% |
| The plan contains an action piece to help the person move towards a preferred lifestyle - outlining what is to happen, who is responsible and by what date the action is to occur. | No | No | No | No | 0% |
| The plan contains an action piece to help the person stay healthy and safe outlining what is to happen, who is responsible (by name) and by what date the action is to occur. | No | No | No | No | 0% |
| The plan contains a review date at which time the person and significant others meet and follow up. | No | No | No | No | 0% |
| Percent of Total | 11% | 33% | 33% | 0% | 19.5% |

What We Learned About Service Coordination.

Idaho has an independent service coordination model that allows individuals to choose the person that helps develop the service plan, lines up community resources, and provides follow-up. As previously noted, an agency that furnishes other direct services to an individual cannot also service coordination. Service coordinators are paid a monthly rate per individual supported.

Those persons we interviewed noted that while many service coordinators are exceptional at what they do, the reimbursement rate greatly limits the opportunity to develop a thorough, person-centered plan. In addition, there is currently no differentiation for developing a comprehensive support plan. A support plan for someone living on their own, using paid and natural supports, navigating a community-based, generic resource system is typically a more comprehensive plan.

What We Learned About Rates.

Most individuals we talked and material reviewed seems to have something to say about rates. For example, the Olmstead planning group recommended *raising the HCBS/ISSH cost effectiveness cap to allow waiver participants to use supported living without a roommate when their needs require a higher cost effectiveness cap.*

In regards fund flexibility, the group indicated that *Medicaid billing requirements for community living are burdensome and tied to rigid categories. For example, supported living placements rely on a combination of discrete waiver services which must be performed, documented and billed in units as small as fifteen minutes. Care and supervision for a person may require a provider to switch from one service to another many times each day depending on the activities.*

They recommended that *bundling of services into a single daily rate or billing code and simplifying documentation requirements. This could save considerable time and*

expense, making it easier for supported living providers to serve more consumers and meet more diverse needs.

When asked what it would take for an agency to start offering supported living services, one provider indicated that the process of developing individual supports and a service contract would need to look like the following:

- an individual selects a provider;
- the individual (and others in the individual's circle of support) and the service coordinator describe a preferred lifestyle to the provider (e.g., characteristics of a home, with or without housemates, what a typical day and weekend would look like, hopes and dreams, goals for greater independence);
- the provider develops a service plan and an individual budget and suggests ways to support the person (e.g., type and frequency of support staff);
- the individual budget is negotiated with the individual and service coordinator and a service contract is established by the Access Unit.

Another individual reiterated the above by suggesting that rates and reimbursement procedures should be simplified such that one could sit down with the person and those who know them well, work up a reasonable plan, designed to provide a decent and preferred lifestyle, negotiate costs and services, add up the costs and an individual budget is created.

When asked about current rates and funding structures, another individual suggested that Idaho has created a system that requires providers and individuals to justify every 15 minutes of 'billable' time. Those 15 minutes blocks must be linked, documented to a specific goal and rates. Also, providers appear to have used

developmental therapy as a means to make up for the low residential habilitation rates. Individuals, therefore, may be forced to develop and work on goals that are undesired or useless. The bottom line is that it looks like 'make' work has been created to justify a payment.

As previously noted, in order to make the low rate for residential habilitation work for providers, we were told that a 'package' including developmental therapy and behavioral services is typically provided to individuals. As we have also indicated, this package by its nature excludes individuals who may need less than 24 hour a day support. Using the example of the SLS agency in Napa for comparison sake, the range of monthly reimbursement for individuals supported is from \$450 to \$8,285. For a similar agency in Idaho, the monthly range is reported to be from \$5,800 to over \$10,000.

Finally, the service 'package' as it has developed now typically includes three to five separate contracts between the provider and the State. In addition to multiple monthly claims, each contract includes an annual audit and monitoring review. This replication of effort creates a significant cost to both the State and the provider.

What We Learned About Developmental Therapy.

The only other area of consensus across the individuals we interviewed (in addition to the important value of SLS for supporting the movement of individuals from the institution to the community) seemed to be that other than as an important funding stream, developmental therapy serves little purpose. In fact, it is considered by some to be intrusive and restrictive.

For example, it was reported to us by a service coordinator that one of the individuals she works with decided to move into a Certified Family Home because he was tired of

the 'programming' (also known as developmental therapy). He later reported that he felt more in control of his life in his new living arrangement.

An individual who uses SLS services indicated to us that while she knows most everything that she is being taught, it was an okay way to spend her day. Another individual was a bit more blunt in stating that she felt as if she was a prisoner in her own apartment. She was referring to the 'mandatory' training that she was involved in each day, most of which occurred in her home.

The Olmstead planning group eloquently stated that *some people will always need some level of support due to medical needs, functional abilities, or maladaptive behavior. This should not prevent people from living in integrated settings with adequate supportive services.* They referred to this barrier as the "readiness" model. Developmental therapy, in the manner in which we were told it is presently delivered in SLS (e.g., charts and notebooks in hand at the local WalMart), is a "readiness" model. While teaching functional skills in 'natural' environments at 'natural' times (using non-intrusive teaching and data collection methods) is common, developmental therapy as described to us by many individuals is not a typical element of a supported living service.

What We Learned About the Future of Supported Living Services.

We have gathered from the individuals that we interviewed that at this time, there appear to be few incentives to plan for, use or provide supported living services in Idaho. In fact, within a year or two, it is the opinion of some that there will likely be fewer individuals supported in their own homes using Medicaid waiver services and that there will likely be fewer providers.

Considerations for Expanding the Use of Waiver-Funded Supported Living Services in Idaho

Introduction.

The challenge we were given was to develop a report that suggests an approach to creating a supportive environment for those who plan for, use and provide supported living services. The considerations we offer here for expanding the use of waiver-funded supported living services in Idaho are not likely new to the reader. In fact, for the most part, they represent the thoughtful reflections of the Idahoans who talked to us. These considerations were collected from individuals, families, service coordinators, State agency staff, service providers, and advocates. From what we have read, at least some of these recommendations have been made to the State more than once over the last six years. As a report on self-determination (Idaho State Governor's Council, 1998) for Idahoans with developmental disabilities stated *none of these recommendations are new, just do it.*

Questions that Still Need to Be Answered.

While we offer some considerations for making short and long-term changes to the waiver and other policies and procedures, at some point, stakeholders still need to answer several questions:

- What is it that Idahoans have in mind when they use the words “supported living”?
- By whom are the services going to be delivered (e.g., single service agency, menu based and multiple service agencies, a combination)?
- Is beneficial to have a separate, supported living rate system or a system for determining broader-based, individual budget allocations?

- Is beneficial to have a separate, quality assurance and risk management system for supported living or a statewide system for all services?

What We Learned from Idahoans.

As was the case with describing challenges, most individuals we talked to offered an opinion about how to change the way that waiver-funded supported living services are provided. Across all of those individuals (e.g., state agency staff, providers, advocates), there does appear to be some agreement that: (1) as previously stated, supported living services have been a valuable element in helping people move from ISSH to the community; and (2) expansion of this service option would make sense. In addition, as interviews and e-mails proceeded, some basic elements of a change proposal began to emerge.

Considerations for Short-Term Change in a Nutshell or 'Tinkering Around the Edges.'

One individual representing a State agency very succinctly described all of the elements we heard from others as: (1) developing a strategy for providing the start-up costs associated with moving into your home; (2) re-educating service coordinators, individuals and their families, state staff and advocates about person-centered planning and supported living; (3) changing the reimbursement structure to allow for more flexibility in service arrangements; and (4) moving to outcomes that reflect everyday life and are not driven by a medical model. Some of these elements for change are short and others long-term, some are cost effective or neutral and others have additional cost implications. However, if implemented, it is likely that the use of waiver-funded supported living services would increase. It is also likely that these changes would only provide short-term success.

Start-up Costs.

As previously mentioned, waiver funding can be used to offset some of the initial costs of living in a place of your own. For individuals moving into the community from

institutions, service planning and accessibility modifications can be completed prior to the move. This option would have to be considered a cost effective one if the State does not currently claim for these services. While other options for start-up are not waiver-funded and have some cost implications, there are a variety of possibilities that could be pursued.

For example, the Social Security Administration has piloted waivers in four states to the \$2,000 limit for establishing something called an Independence Accounts. This type of account could likely be used to establish someone in a place of his or her own. There is also a nationwide advocacy effort to create a Home Account that would allow for a waiver of the \$2,000 limit. Or, state staff, providers and advocates could establish a regional approach (e.g., fundraising, community-based philanthropic foundations) to developing a fund for furnishings, and first and last month's rent through grants or no or low interest loans. Tracking the number of persons who choose supported living services before and after implementation would serve as a measure of effectiveness.

Person-Centered Planning.

Several years ago, in a report about Idaho's Home of Your Own Initiative²⁷, it was recommended 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.* More recently, CMS has encouraged auditors of waiver plans to look for evidence that waiver participants have input into their plans and that lifestyle preferences are considered.

There does not appear to be adequate capacity or funding to support the development of person-centered plans and successful supported living services

²⁷ *Supporting Idaho Citizens with Disabilities to Have a Home of Their Own*, a report to the Home of Your Own Initiative by Gary Smith.

require one. It is recommended that service coordinators and providers be offered training and ongoing technical assistance in a comprehensive person-centered planning process such as Essential Lifestyle Planning (ELP).²⁸ A number of states have provided training in this process and CMS has highlighted the process in Michigan as an exemplary practice.

Using ELP as an example, the process documents how to successfully support individuals in any living arrangement. Once completed, the plan offers answers to the following core questions²⁹:

- What is important to the individual? What are his or her lifestyle preferences, daily routines, likes and dislikes?
- What is important for the individual? What are the issues of health and safety? What do others feel will contribute to an individual's health and well-being?
- What is the balance between what is important to and for an individual?
- What do others need to know or do to best support the individual?
- What are the characteristics of people who can best support an individual?
- How does an individual communicate lifestyle preferences, likes and dislikes, and basic emotions across different environments?
- What needs to stay the same and what needs to change? This drives the development of an action plan.

The short-term costs for this element of the change package would be approximately

²⁸ Allen, Shea & Associates are involved with a number of ELP development initiatives, but do not typically provide training and do not have an economic interest in training materials.

²⁹ Excerpted from *Planning For Yourself* by Michael Smull and Bill Allen for the Michigan Department of Community Health.

\$1,000 per service coordinator (based on estimated daily wages, training costs and materials). In order to effectively implement this change, it estimated that an additional sixteen hours of assessment time for service coordinators would cover the development of such a plan when individuals choose to live on their own with waiver-funded supports. While these additional hours have a cost implication, it is very likely that a savings would offset these costs in the hours spent by both service coordinators and providers in the current 'trial and error' method of figuring out how to successfully support an individual. Tracking changes in staff, roommates and living arrangements before and after implementation would serve as a measure of effectiveness and an offset for this additional cost.

An additional recommendation in this area would be the completion of a person-centered risk assessment and the development and monitoring of an individual quality assurance plan by the service coordinator for individuals using supported living services. Three additional 'development' hours and two additional 'monitoring' hours per month would likely fund this additional service. Tracking the frequency and type of incident reports and funding for short-term crisis services before and after implementation would serve as a measure of effectiveness and an offset for this additional cost.

Reimbursement Structure.

A number of changes must be made in order to alter the reimbursement structure for waiver-funded supported living services. First, the addition of a definition of supported living services to the waiver that is broad enough to cover supports outside the home. For example, it's hard to imagine a definition more inclusive of the services and supports needed in everyday than the California definition (previously stated). If crafted appropriately, this definition would cover the major services (e.g., residential habilitation, behavior consultation, developmental therapy) and others as well (e.g., nursing, evaluation). Provider qualifications could be changed to reflect this expanded service (e.g., nursing services are provided by a nurse, evaluations

provided by an appropriate specialist).

This definition would also set the standard for service expectations that would reflect the basic tenets of supported living and self-determination (e.g., choose of living arrangement, with whom to live, preferred lifestyle). Finally, it would complement the implementation of person-centered planning as individual plans would need to fully describe individual support needs rather than prescribe types of service (e.g., residential habilitation).

A single rate for that comprehensive service could then be developed. Tiers for individuals who choose to live together or by intensity of service³⁰ need could also be developed. While a method for determining a single rate is better developed by Idahoans, here is a simple scheme for establishing a 'draft' rate for discussion purposes. If you average the total daily cost for providing all services to individuals now in supported living services and considered to be at low, medium and high cost and divide by sixteen (the number of typical 'waking' hours per day), an hourly rate could be established. Using a small sample of individuals and this formula, we calculated an hourly rate of \$15.63. An 'exception' process could be established for individuals needing more than sixteen hours per day of support at a negotiated rate for 'awake' or stay over support staff.

This change would produce positive outcomes for individuals with developmental disabilities, providers and the state. First, it would add flexibility to the way services are provided and that would benefit individuals and providers. It would allow individuals more control in where they live and with whom and what they do during the day. For providers, it would decrease the amount of paperwork associated with unneeded or unwanted developmental therapy or behavioral services.

³⁰ This would bring into play the current issue (among advocates) of using the SIB-R as an indicator of service need. There is information that suggests it is not a good indicator.

Second, one contract for services (similar to the contract used for providers of service to individuals with traumatic brain injury) instead of three or more would produce a cost savings to both providers and the state in the current practice of processing multiple invoices and completing multiple annual site visits and audits. The cost implications for making this change would vary based on the individual. That is, the cost of providing services to some individuals would likely decrease (since the current structure dictates that providers develop a 'bundle' of low, medium and high cost services in order to create a viable average rate) while others would increase. Tracking the number of 'new' individuals who choose supported living services, differences in their support needs and total hours of support required, geographic distribution, average cost of individuals services and supports, and the number of 'new' providers of the service would be a measure of effectiveness.

Moving to Outcomes.

In the short-term, the State could implement the CMS Quality Framework previously mentioned. The Framework could be used to focus the annual audit on desired outcomes for supported living services. The outcomes need to be 'customized' by state staff, people with developmental disabilities and their families, providers and advocates. However, the following draft outcomes (based on the Quality Framework) provide an outline of quality outcomes for supported living services offered for discussion purposes:

Desired Outcomes for Individual Access

- Individuals and families can readily obtain information concerning the availability of waiver-funded supported living services.

Desired Outcomes for Individual-Centered Service Planning and Delivery

- Services and supports are planned and effectively implemented in accordance with each individual's unique needs, expressed preferences and decisions concerning his/her life in the community
- Comprehensive information concerning each individual's preferences and personal goals, needs and abilities, health status and other available supports is gathered and used in developing a personalized service plan.

- Information and support is available to assist individuals to freely choose among qualified providers.
- Each individual's plan comprehensively addresses his or her identified need for supported living services, health care and other services in accordance with his or her expressed personal preferences and goals.
- Individuals have the authority and are supported to direct and manage their own supported living services to the extent they wish.
- Individuals have continuous access to assistance as needed to obtain and coordinate services and promptly address issues encountered in supported community living.
- Supported living services are furnished in accordance with the individual's plan.
- Regular, systematic and objective methods (including obtaining the individual's feedback) are used to monitor the individual's well being, health status, and the effectiveness of supported living service in enabling the individual to achieve his or her personal goals.
- Significant changes in the individual's needs or circumstances promptly trigger consideration of modifications in his or her plan.

Desired Outcomes for Provider Capacity and Capabilities

- There are sufficient supported living providers throughout the state and they possess and demonstrate the capability to effectively serve individuals in their local communities.
- All supported living service providers demonstrate the ability to provide supported living services and supports in an effective and efficient manner consistent with the individual's plan.

Desired Outcomes for Individual Safeguards

- Individuals are safe and secure in their homes and communities, taking into account their informed and expressed choices.
- Individual risk and safety considerations are identified and potential interventions considered that promote independence and safety with the informed involvement of the individual.
- There are systematic safeguards in place to protect individuals from critical incidents and other life-endangering situations.

- The safety and security of the individual's supported living arrangement is assessed, risk factors are identified and modifications are offered to promote independence and safety in the home.
- Behavior interventions - including chemical and physical restraints - are only used as a last resort and subject to rigorous oversight.
- Medications are managed effectively and appropriately.
- There are safeguards in place to protect and support individuals in supported community living the event of natural disasters or other public emergencies.

Desired Outcomes for Individual Rights and Responsibilities

- Individuals receive support to exercise their rights and in accepting personal responsibilities.
- Individuals are informed of and supported to freely exercise their fundamental constitutional and federal or state statutory rights.
- Individuals using supported living services receive training and support to exercise and maintain their own decision-making authority.
- Decisions that take authority away from individuals using supported living services are considered only after a determination is made that no less intrusive measures are or could be available to meet the individual's needs.
- Individuals are informed of and supported to freely exercise their due process rights.
- Individuals are informed of how to register grievances and complaints and supported in seeking their resolution. Grievances and complaints are resolved in a timely fashion.

Desired Individual Outcomes and Satisfaction

- Individuals are satisfied with supported living services and achieve desired outcomes.
- Individuals and family members, as appropriate, express satisfaction with the supported living services and supports.
- Supported living services and supports lead to positive outcomes for each individual.

Desired Outcomes for System Performance

- The system supports individuals efficiently and effectively and constantly strives to improve quality in supported living services.
- The service system promotes the effective and efficient provision of supported living services and supports by engaging in systematic data collection and analysis of program performance and impact.
- There is a systemic approach to the continuous improvement of quality in the provision of waiver-funded supported living services.
- Supported living services effectively support individuals of diverse cultural and ethnic backgrounds.
- Individuals and other stakeholders have an active role in supported living service design, performance appraisal, and quality improvement activities.
- Payments are made promptly to supported living service providers in accordance with program requirements.

A Statewide Commitment to Supported Living.

Also included in the report regarding Idaho's Home of Your Own Initiative, it is suggested that *all stakeholders need to make a strong commitment to the precepts of supported living.* Further, *that there is uncertainty and a lack of confidence about "supported living."* This does not appear to have significantly changed since the release of that report.

In terms of recommendations, the report indicates that *it will be important to give supported living special project status in order to overcome these problems.* The report also makes the following observations and recommendations that appear to be just as relevant for this report as they were some six years ago:

- *Idaho should launch a multiyear strategy aimed at deepening service system understanding and expertise in supported living. There is a lack of a broad based understanding and appreciation of the essential philosophy and technology of supported living.*

- *However well crafted amendment(s) [to the waiver] 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.*
- *Serious consideration should be given to incorporating provisions regarding supported living into Idaho statutes.*
- *Strongly consider launching a multiyear supported living technical assistance project along the lines first pioneered in Florida.*
- *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.*

'Going Deep'³¹ for Systems Change.

John P. Kotter (1995), wrote about the primary reasons that organizations are both successful and unsuccessful when implementing efforts to change. Two of those principles are presented here as they apply to waiver-funded supported living services in Idaho:

A Sense of Urgency

A sense of urgency about why supported living services need to change must be evident and, at this time, is not.

A Powerful Guiding Coalition

With so many other issues on the table (e.g., state budget shortfall, cuts in Medicaid spending, growing numbers of children with significant behavioral challenges), there does not appear to be either a shared view of the problem or a sufficient level of trust sufficient to create a guiding coalition.

³¹ A football term that refers to passing for long yardage or a touchdown.

Kotter also wrote that an organization has at least two opportunities to reduce their errors in a systems change process. One is at the point of design, the other at the point the error begins to occur. While some suggest that errors were made in the original design of the waiver, Idaho and other states' experience levels were not well enough established. Errors in the implementation of supported living services (e.g., rate structures, multiple service contracts and audits, person-centered planning) started some six or more years ago and some of the changes needed will be difficult and have higher cost implications in the short-term. While we were asked to focus on supported living, it may be that a redesign of the entire waiver(s) might be a more practical consideration³². It may also be that the pressures of cost effectiveness, increased needs for forensic and children's waiver services would create a greater sense of urgency and a coalition around a redesign of all waiver services (and the State policies and procedures that support them) rather than a single service.

Waiver System Restructure.

The State of Pennsylvania has initiated a total waiver system restructure that will likely change the way that waiver services are provided across the nation. In fact, it has been suggested that CMS officials are currently working on ways to offer the system on a national level.

Introduction. Pennsylvanians mention several major reasons for undertaking what is referred to as the Transformation Project³³. First, individuals and families are asking for: (1) more choice and control in the services they receive; (2) a choice of service provider; and (3) control over individual budgets. Second, that CMS

³² If consideration is given to reworking the waivers in their entirety, technical assistance from the CMS funded National Technical Assistance Team is recommended. While the authors of this report are involved with the team, this is not a self-serving recommendation as they do not provide technical assistance with waiver redesign and have no financial interest at stake.

³³ Information about the Transformation Project was collected from interview notes with national consultants and the Pennsylvania Department of Public Welfare website.

requires that states provide data and reports that the State could not produce. Third, that the Health Insurance Portability and Accountability Act requires states to improve and standardize transaction codes to simplify the processing of medical claims and security.

To support a transformation that increases individual and family choice and control as well as reporting, a computer system called HCSIS (Home and Community Services Information Systems) has been built to automate the collection and storage of information. A pilot test of the web-based system has almost been completed in several Pennsylvania counties. Early indications are that it has greatly improved activities in the following primary goal areas:

Quality Management. Ensuring the healthy and safety of individuals receiving services, value for the dollar, and good outcomes.

Individuals and their Families. The system can be used to register for services, support individual service planning, provide a service and supports directory, and develop an estimate of individual resources.

Financial Controls. The software computes the allocation of waiver funds to counties, tracks hearings and appeals as well as fraud and abuse reporting, and processes provider invoices.

When fully functional and phase-in is completed, the system will provide the following services:

- collect and maintain demographic and registration data;
- determine individual profiles and calculate a target budget;
- maintain a standardized individual plan that will include an individual budget;

- aggregate individual budgets to support the allocation and financial reporting processes;
- capture and store provider information;
- improve the provider billing process;
- store operational and provider performance information that will be accessible to stakeholders;
- capture monitoring and evaluation data; and
- integrate monitoring and evaluation data into a comprehensive quality management framework.

Beneficiaries of the Transformation Project. The State of Pennsylvania views this transformations as benefiting everyone as follows:

Individuals using services will be able to: pre-register and receive information when it is most convenient to them; receive an individual budget; choose a support coordinator; develop an individual plan with support as needed; choose a provider or providers of service; and, receive of how individual budget dollars are spent.

Counties will know upon registration, whether funds are available to fund a person's individual plan

Support coordinator roles and responsibilities will be clearly developed which will allow the coordinator to: focus on building a relationship with the individual/family; enhance the effectiveness of the individual planning process; and, use the core system to simulate the cost associated with different provider, service, and duration combinations so that the best possible plan and budget are developed.

Service providers will be able to: provide services anywhere in the state; enter incident reports via the web instead of the standard paper process; and, bill for services using the web.

State staff will benefit by: advance review of information making staff more informed and communications more consistent; standardized mechanisms for external reporting and analyzing data to increase accountability; enhanced operational activities such as budgeting and allocation, risk management, licensing, monitoring of counties, and services and reporting.

An Overview of How it Works. The transformation project will change the way that services are delivered to balance the health and safety of individuals receiving services while giving them greater choice and control over services and supports.

For an individual or family seeking services and supports, the first step is to register for services (e.g., county office, internet, toll-free number). If the individual is eligible, the county works with the individual to determine the amount of funding appropriate for their needs. If the necessary funding is available, the amount is shared with the individual and family to help plan their services.

The individual then chooses a Supports Coordinator who will use the estimated amount of funding and work with the individual to develop an Individual Plan and Budget. Individuals are able to view a Services and Supports Directory that allows them to choose from providers within their county or anywhere in the state.

Once the providers and services are selected and the plan is approved, the individual starts using services and supports. Providers invoice for delivered services electronically. Updates to the individual plan and budget are made as needed, but every individual plan and budget is reviewed and updated on an annual basis.

Once the individual is registered in the system, the State and the County will be

able to monitor the health and safety of the individual (and the quality of the providers through the online incident management system and the health risk profile. To comply with federal regulations, the State and the County will monitor the administration of the federal waiver program and survey a sample of individuals from each county. When all monitoring activities are completed, a plan for any needed corrective actions will be created.

Elements of System Restructure for Idaho and Recommendations for Building Consensus.

The advisory group to this project mentioned a desire to learn from other states. So, in this section of the report, we had intended to outline the waiver practices of other states (previously mentioned) as a long-term solution to both increasing the use of supported living services and producing greater efficiencies and cost-effectiveness for the entire waiver service system. However, the Transformation Project described above encompasses all of those elements. That is, it provides a way to develop a person-centered architecture and individual budget (Wyoming), independent assessment of need (Idaho's Service Delivery Project Pilot), risk assessment and management process (Massachusetts), community services and supports for living on your own (Florida), and a regional, community-based quality assurance system (Kansas).

In conclusion and as previously stated, we view the best chance for building consensus around expanding the use of waiver-funded supported living services is to coalesce around the reformation of the entire waiver system for individuals with developmental disabilities in Idaho. To do this, the state should seriously consider the development of an Independence Plus 1115 waiver. This waiver option would serve as a vehicle to promote self-determination across the full spectrum of services. The flexibility of this waiver would allow the state to recast services and supports unburdened by present federal and state policy constraints. The 1115 alternative

could pose enormous opportunities for a "new beginning" in Idaho.

We would also suggest that, as in Florida, the Idaho Governor's Council is well positioned to facilitate the implementation of this system change effort. While we understand that the short-term costs for this kind of transformation are high, it appears that the long-term benefits of building service system capacity to support self-determination, equity and fairness, cost effectiveness, quality of life, and health and safety are priceless.

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