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Participant-Centered Planning and Individual Budgeting

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Summary

State policy makers and consumer advocates are advancing programs and policies to support community living for all individuals. Operationalizing principles of “self direction,” “consumer direction,” or “participant direction” entails many details. This State Policy in Practice technical assistance document offers concrete information and specific state examples on ways to implement participant-directed planning and individualized budgeting.¹

Major Points

• The Centers for Medicare & Medicaid Services (CMS) have incorporated the adoption of participant-directed planning and individual budgeting in the Independence Plus designation.

• Participant-directed planning reflects a shift toward decentralization of long-term care decision-making from an organizational level to an individual level, where personal preferences and choices are respected.

• CMS defines the individual budget as the total dollar value of the services and supports, as specified in the plan of care, under the control and direction of the program participant (i.e., that portion of the budget being participant-directed). Many states are similarly referring to the individual budget as the amount of funds available to the participant (not just participant-directed services). States have flexibility to specify their own descriptions of the individual budget or the participant-directed budget amount. For the purposes of this publication, the individual budget refers to those services and supports considered under the participant-directed service delivery method for which the participant has choice and control.

• Exemplifying two different approaches, Minnesota and New Hampshire are implementing participant-directed planning and individual budgeting principles in Section 1915(c) waiver programs.

¹ Rutgers CSHP/NASHP Community Living Exchange (2004). CMS officials and representatives from several states gave presentations on participant-directed planning and individual budgeting during a national teleconference hosted by Rutgers Center for State Health Policy for Independence Plus grantees on October 12, 2004. Content was updated in June 2005.
• Minnesota’s prospective budgeting methodology was developed by using a regression analysis, based on data from Minnesota’s Medicaid Management Information System (MMIS) regarding characteristics of persons on the waiver and their expenditures.

• In New Hampshire’s retrospective budgeting approach, individuals discuss their needs and a “map” of potential services to explore options and personalized solutions. Costs are discussed in relation to the individual service plan with consultation on becoming more creative and resourceful in crafting unique, economical approaches to that plan.

• No single individual budgeting approach will meet the needs of any given state. CMS affirms states’ rights to craft their own approach to participant-centered planning and individual budgeting.

Background

Most states are currently taking steps to make it possible for older adults and people with disabilities (including children) to live in their homes and communities with supportive services to meet individual needs. They are also increasingly incorporating the fundamental principle of self direction, consumer direction or participant direction into their service delivery approaches, permitting individuals the option to exercise control and choice in identifying, accessing and managing services they obtain to meet their long-term health care and support needs. CMS defines a participant-directed program as one that permits the participant (or the participant’s representative) to have decision-making authority over the workers who provide waiver services and/or having decision-making authority over a budget for waiver services.² A key element of participant-direction is the ability to direct and manage the delivery of needed services and supports and the Medicaid funds used to purchase them.

CMS formalized its vision for participant direction in its Independence Plus initiative, first announced in May 2002. Based on the President’s New Freedom Initiative and Executive Order 13217, Independence Plus enables states to create Medicaid services that provide maximum choice, control and protections to people with long-term support needs. Independence Plus provides this opportunity through the 1915(c) Home and Community-Based Services (HCBS) waiver program and the 1115 demonstrations under the Social Security Act. According to the new 1915(c) waiver application, Independence Plus offers waiver participants a comprehensive approach to participant direction, including information on necessary safeguards, protections and specified criteria including:

• Participants may hire and supervise their own staff and manage their budget, including purchasing goods and services;
• All necessary supports and protections identified by CMS are provided;

The service plan is participant-led;
- An independent advocate is available to participants; and
- There are clear procedures included in the plan of care regarding a staff back-up plan.

**Participant-Directed Planning**

Participant-directed planning recognizes that all individuals have a right to negotiate and determine how their lives are conducted. CMS identifies participant-directed planning as a process whereby the Medicaid participant leads the development of the service plan and where the participant has the authority and responsibility to manage and make decisions about some or all waiver services. Participant-directed planning reflects a shift toward decentralization of long-term care decision-making from an organizational level to an individual level, where personal preferences and choices are respected.

Creation of a participant-directed plan is a process-oriented approach to identifying the strengths, capacities, preferences, needs and desired measurable outcomes of the participant. The plan should provide a detailed account of the participant’s role in the construction and implementation of the individual plan, as well as assurances that the beneficiary’s choices are continually addressed and integrated into the plan. Participant-directed planning enables the participant, often with the assistance of others freely chosen by that individual, to identify and access a personalized mix of paid and non-paid services and supports from a range of services that span Medicaid and non-Medicaid programs.

When CMS evaluates the participant-directed service plan, a primary concern is for the protection and welfare of the beneficiary. For example, CMS assesses the extent to which the plan includes individualized contingency planning for unexpected situations that could possibly jeopardize the person’s health or welfare. The plan should provide alternative staffing resources in the event that normally scheduled care providers are unable to meet their commitments. Ultimately a sound back-up assures that the individual’s health and welfare are not jeopardized and his or her individual contingency plans are effective. States should make sure there is a risk management process in place, and some type of monitoring process that specifies how the plan will be reviewed, managed, and monitored. Discussion of emergency back-up requirements and state examples can be found in the publication, *State Policy in Practice: Creating Emergency Back up Plans*.

CMS affirms states’ rights to craft their own approach to the participant-directed planning process. Some states have promulgated laws that require participant-directed (referred to as person-centered planning) and individual budgeting in their participant-directed programs. Other states are developing rules and regulations to maximize an

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3 Rutgers CSHP/NASHP Community Living Exchange (2004).
4 Reinhard, Crisp & Huhtala (2005).
individual’s freedom in how they approach their life plans. It is up to states to craft their approach to planning and it can vary from state to state.\(^5\)

**Individual Budgeting**

CMS defines the individual budget as “the total dollar value of the services and supports, as specified in the plan of care, under the control and direction of the program participant.”\(^6\) The individual budget may include Medicaid and non-Medicaid funded services and supports and must have a clear audit trail documenting Medicaid expenditures.\(^7\)

In developing individual budgets, it is recommended that the state:

- Clearly describe the method for calculating the budget based on reliable costs or services utilization;
- Develop a consistent methodology for all involved participants;
- Document a process to review and monitor the budget according to a specified method and frequency;
- Provide individuals with the information they need to understand their budget responsibilities and to manage their budgets and expenditures;
- Provide the participant with the ability to move money from one service to another so the person can actually direct how the money is spent;
- Inform the participant of the amount that is authorized to be participant-directed;
- Define a process for making adjustments to the budget if it does not meet the participant’s needs and assure that the participant is aware of that process;
- Provide procedures to evaluate and track expenditures; and,
- Provide prompt mechanisms to adjust funding in response to individual situations.\(^8\)

**Prospective and Retrospective Individual Budgeting Models**

Individual budgets generally fall into two categories: prospective or respective (see Figure 1). In a *prospective approach* the benefit amount for the individual is determined in advance of the participant-directed planning process. The benefit amount is usually based upon an objective assessment of the participant’s needs. States often apply a statistical model to arrive at a total dollar amount based upon a needs assessment survey. Once the total benefit amount is determined, a detailed spending plan is developed that identifies the individual’s needed services and supports and an implementation strategy is derived.

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\(^5\) Rutgers/NASHP Community Living Exchange (2004).

\(^6\) Rutgers/NASHP Community Living Exchange (2004).

\(^7\) CMS (2003a).

\(^8\) CMS (2004).
In a retrospective model, the benefit amount is determined by assessing a participant’s needs in response to participant-directed planning. Costs to meet the needs are often based on the traditional fee-for-services reimbursement schedule. The participant can then determine a personal spending plan and implementation strategy.

In some cases, states may have hybrids of these two methods. States are free to develop their own, unique budget methods.

![Figure 1: Prospective vs. Retrospective Budgeting Process](image)

**Prospective Method**
- Benefit amount is determined in advance of participant-directed planning (PDP)
- Objective assessment of need determines benefit amount
- Participant determines spending plan, services, supports & implementation strategy

**Retrospective Method**
- Benefit amount is determined in response to PDP
- Participant identifies needs within PDP
- Participant determines spending plan & implementation strategy within the PDP

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Regardless of the budget methodology chosen by the state, the individual budgeting process should be designed in a manner that is straightforward and easily understood by the person receiving support and his or her family. This should include a clear dispute resolution pathway. The process must be flexible enough to accommodate changes in the nature, scope or intensity of the supports identified in the participant-directed plan and funded in the individualized budget. Individuals who are self-directing the services they receive can be expected to experience changes in their support needs over time for a number of legitimate reasons related to changes in their condition, living environment and even job status. While some changes in service needs are minor or temporary, with minimal impact on the person’s budget or plan of care, others may require the construction of a new service plan and budget. In either case, the process of individualized budgeting must be able to adapt to changes quickly and not present a barrier to the identification and implementation of necessary changes in supports.11

**Individual Budget Requirements**

*Determining the Needs Assessment Methodology*

Whichsoever budget methodology the state uses, the process of individualized budget development begins with the needs assessment. Many state agencies perform an initial needs assessment during the intake process when eligibility is determined for the Medicaid program. States employ a variety of means to evaluate service needs, using both standardized assessments and individualized participant-directed planning processes.

Regardless of the approach used, the needs assessment must take into account a wide range of individual and environmental factors that function to either facilitate or hamper the ability of people with disabilities to access the services and supports they need. The need for services is significantly influenced by the nature of the person’s living environment, the available level of unpaid supports, and the extent to which he or she is able to perform activities of daily living without assistance. Support needs can vary widely among people with equivalent functional capacities. For example, two individuals may have the same diagnosis but have significant differences in the nature of the support needed, depending on differences in their financial resources and the level of assistance that is available from family and friends.

*Wants Versus Needs*

The concept of participant-directed services is based on the assumption that individuals receiving support have the right and authority to decide what services and supports will meet their needs and who will provide those services. In answering the central question of how much support is enough, the distinction between a want and a need is important.

A critical component in developing the individualized budget is the process of selecting the services that best meet identified needs and determining the amount, frequency and duration of support to be offered. The participant-directed planning process is ideally suited for this purpose because it brings the individual receiving support together with his or her family and friends, service brokers, case managers and others to identify the supports to be provided to meet identified needs. Budgeting for these needs is the priority.

The distinction between a want and a need is an important part of the participant-directed planning process. State Medicaid programs operate within a context of limited resources, expanding demand, and state constitutional requirements that prevent deficit spending. Individualized budgeting strategies must balance policy commitments to choice and control, and support for the principles of self-direction, with the obligation to provide eligible individuals with medically necessary services identified in their Medicaid plans of care. This delicate balance cannot be maintained in the absence of an effective process to distinguish a person’s needs from his wants. In a system where services are individualized to accommodate each person’s unique life situation, it may be impossible to draw a distinction between the two, as one person’s want may be another person’s need. States legitimately use a variety of means to evaluate medical necessity and the extent to which identified needs will be addressed by funded supports. Whatever approach is used, for people to have confidence that their needs are being appropriately addressed it is essential that the assessment process be open, fair and understandable.

A number of states (e.g., Connecticut) distinguish between wants and needs through the negotiated participant-directed planning processes. State approved guidelines may be used to focus discussions on the person’s current status of support and the areas where additional assistance is needed. The process is used to identify: 1) the person’s specific needs for support and training; 2) the scope and level of services necessary to meet those needs; 3) potential service providers; 4) program costs; and, 5) potential generic sources for community-based assistance. The process results in a plan of support that identifies specific services to be provided and funds that may be allocated to meet the individual’s needs.

Several states (including Wyoming, Kansas, and Minnesota) identify general support needs and, in some cases establish a level of support to meet those needs, through a standardized assessment process using standardized assessment tools (e.g., the Individual Client Assessment Profile (ICAP), the Developmental Disabilities Profile (DDP), the Minimum Data Set (MDS) for HCBS, or other state specific instruments). Some state agencies use these instruments both to evaluate functional characteristics and, through statistical analyses, to determine the individual budget.

Many states use a combined approach that integrates standardized assessments of individuals’ strengths and needs into the participant-directed planning and program development process. This approach may employ different evaluative tools to address particular issues or aspects of the individualized budget development process to differentiate those conditions that require immediate attention and funding from service requests that are not critical to health and welfare. Officials from South Dakota, Utah and
Rhode Island use this approach to separate a person’s treatment needs from non-funded wants through the development of an individual profile based on: 1) information provided by two different assessment instruments on functional and situational status; 2) personal data provided by the individual, family and friends; and, 3) professional judgment based on individual assessment.¹²

**Applying the Participant-Directed Planning Process to Individual Budgeting**

All persons, irrespective of cognitive or physical limitations, can self-direct when adequate supports are provided to them. To actively participate in the individualized budgeting and support planning process, the individual or his representative must have the information shown below in Table 1.

<table>
<thead>
<tr>
<th>Table 1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Information needed by the Participant or Representative</strong></td>
</tr>
<tr>
<td>• The methodology used to develop and calculate the individualized budget.</td>
</tr>
<tr>
<td>• The total dollar value of the supports and services authorized.</td>
</tr>
<tr>
<td>• The policies and procedures that apply to the participant’s management of the individualized budget.</td>
</tr>
<tr>
<td>• The policies and procedures an individual may use to delegate responsibility for budget oversight and management to another person acting on his or her behalf.</td>
</tr>
<tr>
<td>• The program limitations and allowable and non-allowable expenditures or uses of the individualized budget.</td>
</tr>
<tr>
<td>• The steps that the individual must follow to request an adjustment to the individualized budget or to resolve disputes regarding services, policies or procedures.</td>
</tr>
</tbody>
</table>

**Design Options for States**

States have broad flexibility to create an individualized budgeting process. There are three basic questions that must be answered when designing an individual budgeting system:

• Who will be served?
• What services will be provided?
• How much will the services cost?

¹² NASDDDS (2003).
Table 6, developed by the National Association of State Directors of Developmental Disability Services (NASDDDS) illustrates these three questions and indicates the determinations and information required to identify the individual receiving the services, what services are to be provided, and how much they will cost. It is important to note that each of the activities is accomplished within the context of ongoing service delivery and generally as a part of a larger system change effort. In many states, the opportunities to receive participant-directed supports and utilize individualized budgets are limited to pilot or demonstration projects that are nested within the existing service system. The manner in which each issue is addressed by the state is as important to the success of the project as are the specific structural changes that may be implemented.

States may elect to discount participant-directed services to ensure cost/budget neutrality. In other words, if the participant-directed services are based exclusively on the estimated cost of traditional services in the plan of care, the expenditures under self-direction may take into account vacancy rates in more traditional service delivery models, which serve to increase costs. If states intend to discount participant-directed services, the waiver application or amendment must describe the justification for such discounts.
<table>
<thead>
<tr>
<th>Table 6: Individual Budgeting Decision Process</th>
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<tbody>
<tr>
<td><strong>Basic Question</strong></td>
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</table>

**Who** will be served?

*Outcome: Identify recipient*

1. **Eligibility for Services**
   - What are the eligibility criteria?
   - How is eligibility determined?
   - Is eligibility based on categorical or functional measures?
   - Are services to be limited by eligibility category?

2. **Funding Priorities**
   - Are benefit limitations applied?

**What** services are to be provided?

*Outcome: Set support plan*

1. **Identification of Needs**
   - How are needs determined?
   - How are needs requiring support distinguished from those that do not?

2. **Identifying Supports to be Funded**
   - What is the process for identifying the supports to be received?
   - Is the process consistently applied?

3. **Natural Supports**
   - Which identified needs are best met by existing informal supports?

4. **Scope of Services**
   - What is the historical pattern of service funding and approval?
   - What is the scope of services that have traditionally been provided to people at similar levels or need?
   - What types of supports are required, restricted or excluded?

**How Much** will be paid for services?

*Outcome: Set budget amount*

1. **Assigning Costs to Services**
   - What is the evidence upon which rates are based?
   - Is the budget development methodology consistent throughout the state or jurisdiction?
   - Are costs in line with historical trends?
   - Are reimbursement rates preset or based on current costs?

2. **Benefit Limitations**
   - Are services limited by restrictions set through regulation or policy?

   - **Individualized Budget Methodology**
     - Does it respond to changes in service need?
     - Does it respond to individual choice?
     - Is there a process for appeals and dispute?
     - Does it make sense to consumers and families?

State Examples

The degree of variability between states in the design and operation of their individualized budgeting methodologies makes it difficult to identify a particular state or program as an example of “best practice” in any particular area. This document features two states that use different budget methodologies to provide concrete examples of prospective (Minnesota) and retrospective (New Hampshire) approaches.

Minnesota – A Prospective Individual Budget

Background

Minnesota’s Consumer-Directed Consumer Supports (CDCS) allows consumers to use an individual budget to customize home and community-based Medicaid waiver services. CDCS, first offered in the Mental Retardation/Related Conditions (MR/RC) waiver in 1998, allows individuals the opportunity to direct their own staff and purchase goods and services (employer authority and budget authority) in six home and community-based waivers.

During the State’s 2002 and 2003 legislative session, legislators voiced concerns that substantial variation existed in the methods by which counties determined Medicaid participant’s individual budgets. Additionally, wide variations appeared in the level of flexibility allowed by counties regarding changes requested by participants in the spending plans of the individual budget. Specifically, concerns included: 1) inequitable treatment of participants; 2) questionable use of public funding by some participants; 3) lack of state control and guidance; 4) inexperienced county management; and, 5) a general need for a statewide system that applies equitably to all.

Concurrently, Minnesota prepared waiver amendments to expand the CDCS service to all of its home and community-based waivers. Minnesota state officials sought to develop a standard, state-wide budget methodology for CDCS that was consistent across the state and customized at the county level to provide the most appropriate solutions for participants’ needs using the CDCS service under all of the waiver programs. At the fiscal level, Minnesota’s goal was to develop a new budget methodology that met federal requirements that included:

- Developing a budget methodology that applied to all users of CDCS, even those already having a CDCS budget;
- Granting Minnesota the authority to transition current CDCS participants to the new budget methodology over a period of time;
- Demonstrating that the budget for the waiver would continue to meet cost neutrality requirements (DHS was also required to meet additional state budget neutrality requirements);
- Tracking purchases of CDCS users through the establishment of billing codes that would allow the federal and state governments to monitor and audit CDCS use; and,
• Requiring that each CDCS beneficiary in Minnesota have one Medical Assistance (MA) vendor to do all CDCS billing for goods and services purchased.

After many months of negotiation about the budget methodology and other rules governing CDCS, Minnesota’s application for an amendment to the state’s waiver plan was approved by CMS in March 2004. The approval allowed a six-month preparation period before new policies were activated and a new budget method was implemented. The approval also allowed additional time for transitioning people who already were using CDCS to the new budget plan. The federal approval stipulated that as of October 1, 2004:

• Adjustments were available to CDCS users who were entitled to increases in their budgets under the new methodology, after a revised service plan was completed;
• Downward adjustments were to be completed one year after the next annual review for current CDCS users who were entitled to less money in their CDCS budget, with no transition to extend beyond April 1, 2006; and,
• CDCS users who decided to leave the CDCS option were to remain entitled to all other waiver services that were required to meet their needs.  

Minnesota’s Program Practices
The CDCS service became operational on October 1, 2004 in all counties where CDCS was offered in the following programs:

• Community Alternative Care (CAC) Waiver
• Community Alternatives for Disabled Individuals (CADI) Waiver
• Elderly Waiver (EW)
• Minnesota Disabilities Health Options (MnDHO)
• Minnesota Senior Health Options (MSHO)
• Traumatic Brain Injury (TBI) Waiver

The Prospective Budget Process
In keeping with the prospective budget approach, the participant is provided with the amount of the budget prior to selecting services to be included in the Community Support Plan (CSP) or plan of care. The participant’s individual budget is calculated based upon a regression model, which applies a formula to data from the assessment of the participant’s functional and medical limitations and capacities.

The regression model was developed based upon a sample of 11,697 waiver recipients who received MR/RC waiver services in calendar year 2003, and who continued to receive services in calendar year 2004. The analysis looked at the costs for services during calendar year 2003. Actual costs were used (not authorized levels) to

assure that cost neutrality was maintained. In addition, half of the case management costs for each individual were set aside to insure that counties were paid for the case management functions they are required to do under Minnesota law. In analyzing the sample, DHS identified the characteristics that most influence or predict costs. Those characteristics are considered across all recipients when establishing an individual budget amount. In this way, DHS attempts to address the desire for people with similar needs and situations to be entitled to similar budget amounts under CDCS.

After completing initial research and running statistical models, DHS tested the proposed formula. Testing included studying how the formula performed when compared to actual service costs and utilization in 2003. DHS also studied the impact of the formula on each county’s budget. Since the county has no say in either increasing or reducing the formula amount provided to individuals, DHS had to ensure that sufficient funding remained in place to continue to provide services to recipients not using CDCS. This included identifying and analyzing: 1) the CDCS recipients that were likely to leave the CDCS option because the formula amount was not as high as their current amount; and, 2) analyzing which people would likely choose to enter the CDCS option because it provides them with more funding. Finally, this all needed to be done without increasing state spending.

From the earliest stages of discussion, DHS openly addressed the advantages and disadvantages of a formula approach. This approach does ensure improved consistency and equity in how budgets are established for consumers. For example, if a person changes his or her residence to another county, the CDCS budget would remain the same, and is portable. Using a statistically-based formula to set an individual budget insures that the budget amount provided to an individual reflects an average cost for a group of people or a particular characteristic.

Because Minnesota’s MR/RC Waiver was originally developed to convert institutional services to community alternatives, the approved waiver plan has never imposed an individual cap on the amount that a county could authorize for an individual person. Instead, counties are responsible to remain within an allowable budget. This has provided flexibility to serve people with extremely challenging needs, including people with long institutional histories and no active family involvement.

In general, a maximum monetary resource allocation is determined for a time period of one year. As stated above, individuals may develop their CSP up to the entire dollar amount allotted to them by the state, but the county has final approval over the actual CSP. Beneficiaries may use less than their maximum funding without penalty. Individuals are encouraged to be prudent with their resources, and part of the job of the County Case Manager is to provide advice to the individual on how funding can be allocated to meet all of the person’s needs within a specific funding period. Changes in the original service plan can be made throughout the duration of the year, without any loss of funds from the maximum. If a person does not use the maximum, it does not affect the total dollars that can be allotted for the next year. Annual assessments are made independently of previous usage. This type of allocation distribution has been practiced
for MR/RC waivers for a number of years. EW waivers are operating on a case-mix model, so the CDCS budget component for this waiver is only allotted based on a proportion of the case mix amount.\textsuperscript{14}

The strengths, weaknesses, and process identified above are similar to how the budgets were determined for the CAC, CADI and TBI Waivers. However the data source is the Long Term Care Screening Document.

For a complete description of the budget methodology see:

\textbf{Participant-Directed Supports}

The system by which Minnesota provides a system of supports to those electing to manage their own services is noteworthy. County Case Managers and flexible (i.e., “optional”) case management, both waiver services, comprise this system. County Case Managers are assigned to each waiver participant and represent the first point of contact with the CDCS applicant. Services provided under case management include:

- Screening and assessment to determine if the person is eligible for waiver services including level of care requirements;
- Providing the person with information regarding home and community-based alternatives, so they can make an informed choice;
- Providing the person with an individual CDCS budget if the person elects CDCS;
- Providing the person with resources and informational tool kits to assist in managing the service;
- Evaluating that the person’s health and safety needs and assisting the participant in developing his or her Community Support Plan (CSP), which documents the services that are selected to meet his or her needs;
- Reviewing the CSP and MMIS Service Agreement, including rates; set limits by service category;
- Authorizing waiver services;
- Reviewing and authorizing additional funding for environmental modifications or assistive technology exceeding $5,000 and additional quality assurance if it is manageable within the county’s overall waiver allocation;
- Managing waiver spending within the county’s allowable waiver allocation;
- Monitoring and evaluating the implementation of the CSP, including health and safety, satisfaction and the adequacy of the current plan and the possible need for revisions;
- At a minimum, reviewing the person’s individual CDCS budget and spending before the third, sixth, and twelfth month of the first year of CDCS services and at least annually thereafter;

\textsuperscript{14} Rutgers CSHP/NASHP Community Living Exchange (2004).
• Monitoring the maintenance of financial records and the management of the budget and services;
• Providing technical assistance regarding budget and fiscal records management and take corrective action if needed;
• Investigating reports related to vulnerability or misuse of public funds per jurisdiction;
• Contracting with providers and monitoring provider’s performance;
• Completing satisfaction measurements;
• Reporting satisfaction, utilization, budget, and discharge summary information to the state agency; and,
• Having a system for persons to contact the local agency on a 24-hour basis in case of a service emergency or crisis.

In creating the CSP documents, the individual may also be assisted by anyone they select or by a Flexible Case Manager. This waiver service provides information about CDCS and provider options, facilitates the development of a participant-directed CSP, monitors and assists with revision in the CSP, assists in recruiting, screening, hiring, training, scheduling, monitoring, and paying staff, facilitates community access, monitors the provision of services, and provides staff training that is specific to the participant’s plan of care. To qualify as a Flexible Case Manager, an individual must be at least 18 years of age and be certified through an on-line training course by the Department. The participant pays for the cost of flexible case management from their individual budget.

The final evaluation of the CSP is made by the county, to assure that the plan complies with the waiver requirements regarding self-direction, quality assurance, provider qualifications, monitoring requirements, and health and safety. The county can suggest modifications to the CSP if there are concerns about the CSP not addressing the person’s health and safety. The individual can choose to make the suggested modifications or not. If the person chooses to not make the suggested modifications, the County Case Manager can choose not to accept the CSP. If the person does not agree with the required County Case Manager’s decision to reject the CSP, they can appeal that decision. The person and/or authorized representative may minimally revise the way that a CDCS service or support is provided without the involvement or approval of the County Case Manager when the revision does not fundamentally change what was authorized in the CSP. Once the CSP is approved, the County Case Manager must enter the Service Agreement into the Medicaid Management Information System (MMIS).

Once the CSP is in place, individuals can negotiate service rates and choose how much of a particular service they wish to purchase. Exceptions exist, for example when parents of minors or a spouse are paid to provide support, the rate paid cannot exceed the rate the state pays for state plan personal care attendant (PCA) services (currently that rate is $14.92 per hour). Additionally, when beneficiaries use case management or
planning supports external to the county, that rate cannot exceed the maximum allowable for county-based case management services.\textsuperscript{15}

When choosing to pay parents of a minor or spouse, the following case management activities are required in addition to those mentioned above:

- At least quarterly reviews by the county on the expenditures and the health, safety and welfare status of the minor/spouse.
- At least semi-annual, face-to-face visits with the minor/spouse.\textsuperscript{16}

Minnesota is currently developing a provider called Fiscal Support Entity (FSE), which serves as the Medicaid provider for all CDCS. Charges for that provider must be included in the individual’s CSP. The FSE Medicaid providers will make their rates public and must have contracts with the county. Those rates will be given to the consumers, and the consumer will customize what they purchase from the FSE from a variety of services offered. These costs are included in their individual budget plan.\textsuperscript{17}

Minnesota has developed a number of resources to assist consumers in directing and managing their own supports, including:

- Consumer Directed Community Support Brochure
- Consumer Directed Community Support Consumer Manual,
- List of Fiscal Support Entity (FSE) providers
- Access to on line training modules through the College of Direct Support
- Numerous on line informational resources at \url{www.dhs.state.mn.us}

\textbf{Program Results}

In September 2004, the Minnesota DHS awarded a contract to an independent auditor to conduct an evaluation of CDCS. The goal of this project is to evaluate CDCS policies and procedures to determine if they achieve stated outcomes within the parameters of the state-approved waiver amendment.

A preliminary report to the Minnesota Legislature in February 2005 was scheduled to summarize evaluation progress, preliminary findings and recommendations. An interim report is due June 2005 with a final report due January 2006.\textsuperscript{18}

\textbf{New Hampshire – A Retrospective Individual Budget}

\textbf{Background}

Since the mid-1980s, New Hampshire has had a continuing commitment to developing a system of home and community-based services and supports for people with

\textsuperscript{15} Rutgers CSHP/NASHP Community Living Exchange, (2994).
\textsuperscript{16} Minnesota Dept. of Human Services, (2004b).
\textsuperscript{17} Rutgers CSHP/NASHP Community Living Exchange, (2004).
\textsuperscript{18} Minnesota Dept. of Human Services: CDCS (2004c).
developmental disabilities. Reforms have been implemented with a focus on participant-directed planning, integration of support services and self-direction. The state has actively implemented these principles over the last six years, and currently has several programs that offer participant-directed services in varying degrees.\textsuperscript{19} The Medicaid HCBC-DD waiver for adults with developmental disabilities includes a participant-directed services program that allows participants to have significant control over allotted funding. In spring 2003, New Hampshire obtained an \textit{Independence Plus} waiver for children with developmental disabilities, called the In-Home Support waiver. This HCBS waiver, the first \textit{Independence Plus} waiver approved in the nation, was modeled on the existing adult HCBC-DD waiver. In addition, New Hampshire has two other waiver programs (Acquired Brain Disorder waiver and the HCBC-ECI waiver) and a state plan service that employs self-direction.\textsuperscript{20} There are now approximately 140 families in New Hampshire managing their supports through self-direction.\textsuperscript{21}

Consumer-choice and consumer-direction were already established practices in New Hampshire when \textit{Independence Plus} was enacted. New Hampshire identified the \textit{Independence Plus} initiative as an opportunity to expand upon existing self-direction programs. State officials had observed that under existing developmental disabilities programs for children, many parents experienced difficulties obtaining supports that met their specific needs for in-home care for their children. Families were limited to services prescribed for them by professional gatekeepers who were disconnected from beneficiaries’ individual situations. Participants found that they were restricted to services that often did not meet their unique range of needs. Within these boundaries, many found it difficult to identify or access the services that would enable them to continue in-home care of their children with disabilities. New Hampshire’s enactment of the \textit{Independence Plus} initiative for this consumer group was intended to empower the family to assess its own needs and to enact a participant-directed support strategy that would deliver the resources to create a better in-home care environment.\textsuperscript{22}

\textbf{New Hampshire’s Program Practices}

The New Hampshire Department of Health and Human Services (DHHS) administers the Medicaid program, as well as programs in developmental disabilities, mental health and substance abuse, disability/chronic illness, and the child welfare program. The Division of Developmental Services (DDS) within DHHS administers Medicaid waiver programs, and also has responsibility for overall developmental disabilities policy.

All of the state’s developmental disabilities participant-directed programs feature a single point of entry through twelve geographically-based Developmental Services Area Agencies (Area Agencies). The Area Agencies, which were established early in

\textsuperscript{19} Rutgers CSHP/NASHP Community Living Exchange, (2004).
\textsuperscript{20} Medstat (2003).
\textsuperscript{21} Rutgers CSHP/NASHP Community Living Exchange, (2004).
\textsuperscript{22} Rutgers CSHP/NASHP Community Living Exchange, (2004).
New Hampshire’s HCBS movement, arose from existing private, non-profit community support organizations that had well-established local connections that could effectively execute the concept of delivering personalized services to individuals with disabilities. They currently provide services to all persons with developmental disabilities in their region, whether or not participants receive Medicaid coverage. These Area Agencies also serve as the single point-of-contact for both adult and child beneficiaries for as long as they require supports.

The Area Agencies provide a community-based one-stop resource for a broad range of developmental disabilities services. They manage almost all components of the community-based service system, including enrollment, program management and coordination of service delivery. The Area Agencies have the power to adapt their service provider pool to meet the specific needs of its local consumer group. Some of the Area Agencies provide services directly, others subcontract for services through third-party vendors, and some do a combination of both.  

New Hampshire’s Independence Plus program, known as In-Home Support, operates under one consolidated budget that groups similar services, including such options as enhanced personal care, and environmental modifications, respite, consultation services and service coordination. It serves approximately 200 children with total funding of $4 million. In order to meet the budget requirements for this waiver, the state must manage the annual average dollar allotment per child to $20,000. In actual practice, DDS has been able to maintain this average while delivering a relatively wide range of total dollars per individual budget, with some allotments reaching the $30,000 maximum defined in the waiver, and more conservative budgets going as low as $12,000 per year.

The New Hampshire eligibility process for Medicaid waiver services has two components. Initially, an individual applies for Medicaid coverage at the state DHSS district office. Once approved, the applicant is assessed for waiver program eligibility based upon a standard form used by all Area Agencies. The Area Agency then assists the beneficiary in the development of a service budget and a person-centered plan, or Individualized Service Plan (ISP) as it is called in New Hampshire. The ISP is approved and finalized at the Area Agency level, with review by DHHS.

New Hampshire developed its waiver program with the goal that it reflects “real needs - real costs, with an eye towards the future.” The ISP is intended to be a means for identifying the resources that the participant needs to meet personal objectives. It includes not only specific services that will be provided, but also defines the life goals of the participant.

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The process for developing the ISP is very personal, depending largely on face-to-face communication between the Area Agency representative, who is called the Account Manager, and the participant. The information exchange process between the Account Manager and the family is very interactive and the development of the ISP unfolds through an iterative process. The initial meeting to begin construction of the ISP takes place between the Account Manager and the participant, usually at the family’s home, employing a “kitchen table planning approach.” During this first meeting, a major emphasis is placed on educating the family about the program’s offerings. This orientation process is tailored to the needs of the family’s decision-makers. Participants often come into these meetings with a varied range of knowledge about benefits and programs. Some participants need extensive orientation to the process, while others come with significant levels of experience in negotiating and evaluating support resources. When interviewing families to determine their support needs, Account Managers try to present the program options in very direct, practical language that is meaningful to those involved. Prior to this meeting, families have received mailings with descriptive information on the program and they have completed a waiver eligibility profile. A major goal for this meeting is to assure that the participant is completely informed of all the support options available through the waiver program.

The Account Manager presents the family with a “map” of potential services from which they can select, within the limits of the waiver program. The Account Manager takes the role of a consultant who guides the family through the process of exploring options and inventing personalized solutions with supports that will have a positive impact on their child’s future.

The next step in the process is to begin to identify “real costs” involved in delivering the selected services, and tailoring the services to meet the family’s needs. The Account Manager views service planning and budget development as “concurrent” activities. Therefore, the discussion moves back and forth in its determination of needs, development of a service delivery approach, and cost analysis. The Account Manager often finds that as the discussion progresses and families gain knowledge about their options, they become more creative and resourceful in crafting their ISP solutions. Through consultation with the Account Manager they are often able to identify alternative resources that they previously did not consider and to then craft unique, economical approaches to meeting their needs.

Through this process families become educated about the costs of services and therefore are able to more effectively manage their dollars. If a particular type of service is extremely important to them, they can spend more of their budget to obtain that specialized level of care that comes with a higher provider fee. Account Managers try to help parents understand how they can make choices to save money in one area so that more can be spent in another. For example, parents are encouraged to consider economies provided through employment of family members, people who require little or no training, or those who can be trained by the parents at no additional cost. However, the

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final ISP is defined by the family’s preferences. Their choices for solutions to meet their unique needs are respected, as long as they remain within the waiver requirements.29

The following serve as guiding principles that New Hampshire emphasizes in the process of developing service planning and an individual budget:

- **Frugality:** These are public funds, which need to be treated as such, as the individual exercises prudent purchasing and management of funds.
- **Payer of Last Resort:** Other generic resources must be utilized first.
- **Compliance:** All parties are reminded of the program’s standards and expectations.
- **Education:** People come into the process with a wide range of knowledge and experience, and they are all educated about the program.
- **Hands-On:** With calculator in hand, the Account Manager sits down at the family’s table and develops an individual budget.30

In creating an Individualized Service Plan, the family has the flexibility to pick and choose from a variety of service components, and to change the services throughout the year. Families have maximum flexibility in selecting service providers and in negotiating the rates paid for supports and services. The Area Agency serves as the enrolled Medicaid provider for the waiver program. The Area Agency uses the Fiscal Agency of Choice model (the Agency is the common law employer while the participant and family are the managing employer) and serves as the Fiscal Agent for the services that families purchase in five support categories: personal care, respite, professional consultation, environmental modification and family support/service coordination.

The Area Agency provides general management services to individuals, such as: orienting the family; providing budget analysis, regulatory oversight, quality assurance and core training to providers; and, serving as a Fiscal Agent. These basic services are paid for through the service coordination and general management fees. In addition to covering the costs for the Account Manager to assist in the development of the ISP, these fees cover general expenses that the Area Agency incurs in the provision of consumer-directed programs, including general administration and business costs.

**The Retrospective Budget Process**

Every person in the waiver program has a budget amount related to their service plan. As part of the orientation to the waiver, families are informed of the financial limits on the individual budget. It is the Account Manager’s responsibility to help families identify their specific needs, and to maximize support for their children. Families are informed of the three basic components of the individual budget:

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• **Family Design Services:** This is the budget amount for direct consumer services; the family receives a voucher to pay for these traditional and/or customized services and supports. A voucher is a statement to the family confirming the annual amount of money that they control out of the total Medicaid funding.

• **General Management Fee:** 10% of direct service costs for fiscal agent services, agency general management and allocated agency expenses. This includes: costs of the Executive Staff, Financial Management Staff and support staff and supplies for the Executive and Financial Staff; Management Information Systems costs for services and financial data; and, Region-Wide Planning and Program Management for developing regional service plans, ensuring service continuity and coordinating client movement through the service system, and developing new services.

• **Service Fee:** The typical cost is $250 per month for case management services ($3,000 per year). This is a combined charge for traditional case management, as well as an account function of budget development, oversight and analysis. As an alternative, a family can elect to hire their own case manager.

Once the ISP is finalized, parents are trained to assist their minor children in the supervision of their workers and management of their budgets, and are provided with more educational material on how to monitor and manage their allotments. The family is responsible for all of the paperwork involved, including submission of payroll, creation of employee job descriptions, and employee evaluation and management. The Area Agency does not provide these services, but families can hire somebody to do care coordination and assist with the paperwork if this is necessary.

To keep families informed about expenditures and remaining funds, the Account Manager provides each family with a monthly financial report. Additionally, families can call the Account Manager at any time to receive a status report on their current budget standings. This direct feedback is a powerful management tool for families. Parents see in black and white the funds being utilized. They are able to determine relative value of the services being purchased and they can choose to conserve, reduce, reallocate and/or otherwise fine tune their child’s supports to maximize the allocated funds.  

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Example of a Consolidated In-Home Support Budget:

$15,033.72  Family Design Services: Direct service costs with complete detail: family receives statement (or voucher) that defines this amount.

$1,503.36  General Management at 10% of direct expenses

$3,000.00  Case Management

$19,537.08  Total billed to Medicaid for year

The individual budget planning is comprehensive and is not specific to just those items and services covered by Medicaid. In this manner, the individualized budget reflects the needs and desires of a participant, and the service agreement can be comprehensive, accounting for all aspects of a person’s life. The availability of a clear audit trail is required for the state to authorize the individual budget.  

Program Results

New Hampshire reports that it has received very positive responses from parents on satisfaction surveys evaluating the program, and very few complaints have been registered. An additional measure of success is the anecdotally reported progress made by the children within the program, many of whom have exhibited measurable progress in developmental skills while living within the community and thriving in these personalized conditions.  

Conclusions

Most of the focus of participant-directed planning and individual budgets involves personal care and related supportive services in a participant-directed framework. In contrast to the traditional service delivery model, participant-directed programs reflect a new set of values, roles and responsibilities that are designed to support individuals rather than organizations. The issues and challenges faced by states as they make a transition from the traditional way of doing business to one that employs individualized budgets differ depending on the structure of each state’s service delivery system and the manner in which services have been funded in the past.

No single individual budgeting approach will meet the needs of any single state. Therefore, this paper provides practical examples of approaches and strategies used by two states. As alternative state examples emerge, we will share them in future State Policy in Practice briefs.

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32 Medstat (2003).
33 Rutgers CSHP/NASHP Community Living Exchange (2004).
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Useful Resources

www.cms.hhs.gov/independenceplus
Provides information on Independence Plus and e-mail links to submit questions electronically to CMS.

www.cms.hhs.gov/medicaid/waivers
Provides information about individual states’ Independence Plus applications and programs.

www.cms.hhs.gov/medicaid/waivers/quality.asp
Provides information about the Quality Framework.

www.cms.hhs.gov/promisingpractices
Provides resource information and states’ promising practices.

www.hcbs.org
Provides resources, articles and reports on self-determination, self-direction and states’ promising practices.


Two manuals are available through the Research and Training Center on Community Living, a division of the University of Minnesota:
- Increasing Person-Centered Thinking: Improving the Quality of Person-Centered Planning - A Manual for Person-Centered Planning Facilitators (PDF)
- Training Person - Centered Planning Facilitators: A Compendium of Ideas (PDF)


University of Massachusetts Medical School. Massachusetts Systems Change Grants: A website for the Massachusetts Real Choice and Independence Plus Systems Change


National Program Office on Self-Determination: Institute on Disability. 7 Leavitt Lane, Suite 101; Durham, NH 03824-3522. http://iod.unh.edu/Self-Determination/index.htm
References


Also see: http://www.arcminnesota.com/CDCS_Flexible_CM.htm


