

Chapter 5: Individual Budgeting

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Chapter 5

Individual Budgeting¹

Individual budgets are a key element in a self-direction program that seeks to increase participant choice and control. Control of the budget enables participants to select and manage the services and items they need to live independently and to more fully participate in their communities. Management of an individual budget affords participants in self-direction programs (hereafter, participants) both the greatest flexibility and the greatest responsibility.

Individual budgeting may mean different things to different disability population groups (hereafter, populations.) For many years, state developmental disability services have used the term to apply to the total resource allocation assigned to each participant, whether or not a self-direction option was available. This Handbook discusses individual budgeting in the context of self direction.

Broadly, the Handbook defines individual budgets as the funds or resources available to participants to meet their needs.² Participants may directly manage their services and expenditures or assign responsibility for this task to a representative. Throughout this chapter, use of the term participant categorically includes representatives, relatives, and support groups when designated by the participant, unless a distinction is being made among them.

A. Essential Elements of Individual Budgeting

An individual budget, expressed in a dollar amount, represents the anticipated cost of services and supports determined to be necessary and sufficient to meet a participant's needs, and over which a participant exercises decision-making authority. A consensus has emerged regarding the essential design elements of individual budgeting.³ In addition to using a process that is straightforward, reasonable, and easily understood, states need to ensure that the process is:

- **Accurate.** The methodology should reflect a valid assessment and provide amounts sufficient to meet participants' needs.
- **Consistent.** The methodology should be consistently applied across the program, state, and eligible population.
- **Reliable.** The methodology should produce consistent results over time with repeated application.
- **Equitable.** The process should ensure that participants with the same or similar needs and circumstances receive comparable budgets. Not only should participants who direct their services receive budgets comparable to

those in the traditional service system (assuming comparable needs), but a rational and fair relationship between the cost of traditional services and the participant-directed budget should exist.

- **Flexible.** The process should allow changes to the budget to be made easily and in a timely fashion to accommodate changes in participants' circumstances and choices.
- **Transparent.** The process should be open to public inspection.

Key components of individual budgeting are: assessing need, developing a service plan, calculating a budget amount, and determining a spending plan. The order in which these activities may be performed can vary depending on the program design. For example, some methodologies calculate the budget amount first, then assess needs and develop a plan to meet those needs. Other methodologies assess needs, develop a plan to meet those needs (typically expressed in service hours), and then assign a dollar value to the plan using a specific formula (i.e., determine the budget amount). Regardless of the methodology, the practice of person-centered planning is the foundation for individual budgeting.

Key Terms

Assessment. Determines what the individual needs.

Service Plan. Develops the plan to meet identified needs.

Individual Budget. Determines the dollar amount to be available for participant-directed services, supports, or items.

Budget Setting. Determines how the dollar amount of the individual budget is determined.

Spending Plan. Determines how the individual budget will be spent—on what, how much to reimburse, who will provide service, etc.

Prospective Budgeting. Calculates the individual budget amount using empirical methods prior to the person-centered planning process.

Retrospective Budgeting. Calculates the individual budget amount through an individualized assessment process using the person-centered planning process.

Practicing Person-Centered Planning

Person-centered planning (PCP) is an overarching philosophy applied to the development, management and evaluation of the individual budget to enable participants to identify their needs and to exercise choice and control in developing a plan to meet these needs and achieve their life goals.⁴

Key principles of person-centered planning are:

- Participants lead all planning activity and decision making and are the primary source of information.
- Participants are furnished with sufficient relevant information and support to facilitate informed decisions.⁵
- Participants direct and manage the planning process in accordance with their identified strengths, capacities, preferences, desires, goals, and support needs.

The PCP approach to service planning does not include a series of strict requirements. Rather, it comprises a body of values, principles, and processes used to tailor planning activities around the individual receiving services and supports.⁶ While the essential elements of person-centered planning apply to all populations, the process varies in how it is applied with specific populations.

Typically, the developmental disability (DD) population focuses on major life goals and decisions regarding living arrangements and locations, companions, education, and employment. The PCP process for the DD population is typically manifested as a structured system and may use a series of tools, checklists, or protocols to guide and document the planning process. For example, “Essential Lifestyle Planning” is a protocol for formally guiding participants in identifying life goals and planning to meet those goals.⁷

In contrast, the system that serves elderly persons and younger adults with primarily physical disabilities uses a less structured approach. Rather than focusing on broadly defined long-term life goals, participants focus on their more immediate goals for daily living; that is, identifying the services and supports they need to perform daily activities (e.g., bathing and meal preparation). Several of the states that received Cash & Counseling (C&C) grants are using a tool specifically designed for elderly persons called Participant Goal Setting. See the Resources section at the end of this chapter for a web address to obtain this tool.

The Michigan Department of Community Health (one of the C&C replication grantees) has made considerable advances in promoting person-centered planning in their Medicaid waiver programs. Through a legislative mandate in early 2000, Michigan established the right of all individuals to have their services developed through a PCP process, regardless of their age, disability, or type of residence. The State is disseminating draft practice guidelines on the PCP process to stakeholders

to obtain their input, is conducting training for providers, and is developing an organizational readiness review tool to assess the extent to which providers are using person-centered planning.

Individual Budget Methodologies

Individual budgets may be used to manage participant-directed services and supports under a variety of funding sources, most commonly, Medicaid. Budgets can be used in the Medicaid State Plan through the §1915(j) authority and in §1915(c) waiver programs. The §1915 (j) authority defines a budget as “an amount of funds that is under the control and direction of a participant when the State has selected the State Plan option for (the) provision of self-directed personal assistance services. It is developed using a person-centered process and is individually tailored in accordance with the participant’s needs and personal preferences as established in the service plan.”⁸

Similarly, the §1915(c) waiver authority defines a participant-directed budget as “an amount of funds that is under the control and direction of the waiver participant when a waiver makes available the Budget Authority participant direction opportunity.”⁹ CMS does not prescribe a methodology for states to use to determine the budget amount. States vary considerably in the methods they use—both in their Medicaid and non-Medicaid self-direction programs.

The Administration on Aging Nursing Home Diversion Grants Program (in 2007 and 2008) encourages grantees to use individual budgets that are: (1) flexible to respond to changing needs; (2) responsive to individualized needs and preferences; and (3) not tied to a particular service, package of services, or types of providers.

While methodologies vary from program to program, during the past decade two basic approaches to determine the individual budget have emerged, the prospective approach and the retrospective approach.¹⁰

In the *prospective approach*, the individual benefit amount is determined prior to the participant-directed planning process. The benefit amount is usually based upon an objective assessment of the participant’s needs often using a statistical model or mathematical calculation to arrive at a total dollar amount or the upper limit for the individual budget amount. Once the total budget amount is determined, a spending plan is developed that identifies the participant’s needed services and supports. This approach allows programs to control costs and project expenditures while allowing participants full control of the budgeted amount.

In the *retrospective approach*, the benefit amount is determined by assessing a participant’s needs and represents a more open-ended process. It is more subjective in nature and is based on individual need rather than empirical data or a mathematical calculation. Once needs are determined, the costs to meet the needs are identified based either on the traditional fee-for-services reimbursement

schedule or other mechanisms. Once participants know the budget amount, they determine their personalized spending plan and implementation strategy. Under this approach, benefit limits may be used to control expenditures.

Regardless of which budget methodology a state chooses, the core components of the individual budgeting process are: (1) determining needs, (2) planning to meet determined needs, (3) setting the budgeted amount, and (4) determining the spending plan. Note that determining needs and planning to meet the determined needs may be components of the same process in both the traditional service systems and in self-direction programs.

Determining Needs

Determining needs is typically based on an assessment of the types of assistance individuals require based on their needs, preferences, abilities, and desired outcomes (i.e., goals). The assessment process takes into account: (1) medical condition(s); (2) functional capacity and limitations, specifically the ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs);¹¹ (3) living arrangements; (4) availability of unpaid supports; (5) social environment; (6) geographic isolation; and (7) behavioral complexities. *The needs assessment determines the need—not how to meet the need.*

The methods states use to perform the assessment vary greatly and often differ within a state according to the population being served. In programs serving persons with developmental disabilities, many states use standardized assessment processes and instruments that are nationally tested and accredited (e.g., the Individual Client Assessment Profile [ICAP] or Developmental Disability Profile [DDP] instruments).¹² In other programs, including those serving elderly persons and younger adults with physical disabilities, instruments may be less standardized but typically assess ADLs and IADLs, as well as medical conditions, behavioral issues, and social and environmental factors.

For example, in Washington, case managers assess participants using the Comprehensive, Assessment, Reporting, and Evaluation (CARE) tool. The CARE tool uses an automated assessment procedure to classify participants into one of 14 levels of acuity to determine the amount of funding available for the service plan. Factors assessed and considered include: clinical complexity, behavior/mood, cognitive ability, ability to perform activities of daily living, and availability of informal supports.

A few states use the Minimum Data Set–Home Care (MDS-HC) assessment tool. The MDS-HC is a comprehensive assessment tool; it assesses multiple factors that determine the need for services, including: cognition, vision, hearing and communication, mood/behavior, social functioning, informal support services, physical functioning (including IADLs and ADLs), continence, medical conditions and medications, and the living environment.

Uniform use of a standardized assessment method is critical to ensure equitable funding of individual budgets. It also helps the state to determine whether budgets are being calculated accurately, consistently, and reliably. Variability in assessment methods can make it difficult for states to estimate and control program costs.

Ensuring consistency can be quite challenging in county-based HCBS programs where the state does not require the uniform application of standardized assessment methods. Successful interventions to ensure equity in such programs include the adoption of a standardized assessment instrument in conjunction with training on the consistent conduct of the assessment process.

Service Planning¹³

Once needs are identified, a plan is developed to address these needs. The culmination of this process is a document referred to in Medicaid statute as the service plan. The service plan may be specific to participant-directed services, such as for State Plan Personal Care, or may be a combination of traditional and participant-directed services, as in many §1915(c) waiver programs.

For the purposes of §1915(c) waivers, the service planning process includes the following components:

- Selection of services that best meet participants' needs, goals, preferences, and abilities;
- Development of a plan to maximize resources and supports available in participants' lives or their communities;
- Determination of the amount, frequency, and duration of services and supports to be authorized;
- Creation of strategies to identify, assess, and manage potential risks;
- Development of a monitoring strategy to ensure health and welfare and oversee the implementation and execution of the plan;
- Identification of the roles and responsibilities of those involved in the implementation of the plan; and
- Creation of individual backup plans for situations that might jeopardize participants' health and welfare.¹⁴

While the above components are required only for §1915(c) waiver programs, it is helpful for all funding sources to identify in the service planning process the key services and supports that must be addressed to safeguard health and welfare and to provide an overall picture of the services and supports available to the individual.

Budget Setting (Calculating the Budget Amount)

States have considerable flexibility in determining individual budget amounts; however, the methods for doing so should be accurate, consistent, reliable, and equitable. It is always recommended that participants be told their budget amounts prior to making a decision about self direction.

States use several methods for calculating the amount of individual budgets, described below. These methodologies (which use historical costs, formulas, and individual assessments) may be used in the prospective or retrospective approach or may be combined. What is important is that states ensure that the methods they use result in budgets that meet participants' needs within program parameters and fiscal constraints.

Historical Costs

Many states derive the individual budget amount from historical Medicaid cost and utilization data, typically retrieved from their Medicaid billing system, the Medicaid Management Information System (MMIS). Historical data are analyzed to make assumptions about a participant's future service use and costs. States may express the resulting individual budget in monthly, quarterly, or annual figures.

States have found this method useful in meeting their financial commitment for budget neutrality (§1115) or cost neutrality, since future costs are based in part on previously incurred costs.¹⁵ However, disadvantages of this method include: (1) lack of historical data for newly-enrolled participants; (2) past utilization may not reflect current needs due to changes in condition; (3) some data may be inaccurate or unavailable and data retrieval may be time-consuming; (4) data may be difficult to analyze due to reimbursement rate increases or policy changes that affected utilization; and (5) claims history provides a view of delivered services that does not reflect under-utilization of authorized services due to access issues, such as labor shortages.

Formulas

Some states employ sophisticated data analyses using mathematical formulas or algorithms to develop individual budgets. Typically, states with these methods have a significant amount of historical data and have devised techniques to identify individual participant characteristics or combinations of characteristics that are likely to influence utilization. An example of such a technique is identifying participant characteristics using the MDS-HC tool described previously.

Such characteristics or variables include medical condition(s), age, mobility impairment, cognitive impairment, behaviors, and many other factors. The formal assessment instrument assigns a weighted score for specific variables, which are then added to reach a total score. The total score is calculated in the context

of other factors such as regional economic conditions—including labor costs—historical expenditures, and funding limitations. The product of these steps is an empirically derived individual budget.¹⁶

Minnesota's formula considers 28 characteristics/variables that have been demonstrated to most influence or predict costs. An annual spending limit or set dollar amount is established based on the scores for the variables, as well as historical costs.¹⁷ The method assumes that the set dollar amount will cover all of a participant's identified needs, but if it does not, the state conducts a reassessment to determine changes in medical and functional needs and makes necessary changes.

Programs in Nebraska, Montana, South Dakota, and Wyoming have been using formula-driven methods for several years. While this approach is statistically complex, states agree that individual budgets calculated in this way reflect the individualized assessment process, historical utilization, and unique state situations, and they agree that this approach can contain costs.¹⁸

Individual Assessment

Basing the budget amount on an individual assessment of needs, goals, preferences, abilities, and desired outcomes has been, in the past, a common approach, particularly in programs serving elderly persons and younger adults with physical disabilities. This approach uses the information provided in an assessment to determine the number of service hours required to adequately meet participants' needs. Once the total number of hours is calculated, this figure is multiplied by the traditional state reimbursement rate(s) or the current fee-for-service rate(s) to obtain the amount of the individual budget.

A major advantage of the individual assessment method is that the individual budget amount matches participants' current needs and is straightforward and easily understood by participants. For this method to meet the consistency, equity, and comparability requirements, however, a standardized assessment process must be used uniformly to determine participants' needs. Otherwise, budget amounts might vary by locality and among individuals performing the assessment. Ideally, two participants with comparable needs and environments should have similar individual budget amounts. Additionally, this outcome should occur whether they are assessed by the same person or different people.

A disadvantage is that unless the individual assessment is standardized and used uniformly across the state, this approach can make it difficult to achieve budget neutrality, cost neutrality, and other state-specific financial constraints. For example, in some states, budgetary constraints require that expenditures for a new self-direction option can not exceed the amount that would otherwise have been spent on services provided by agencies. To ensure this, some states apply a discount or deduction to individual budgets.¹⁹

Alabama and New Mexico apply an automatic discount to the authorized hours in the service plan. Some analysts argue that applying such a discount based solely on historical utilization and the inability of traditional providers to meet demand leaves the state in a questionable position to meet CMS health and welfare assurances by failing to provide adequate services based on current and actual need. Vermont initially discounted individual budgets, but stopped doing so due to complaints from participants and the negative effect it had on program enrollment.

While the amount of a participant-directed budget should not be greater than the cost of traditional services that would have been authorized, it could be less as long as the deduction is reasonable and justifiable (e.g., deductions for the cost of counseling and financial management services). States have the option to cover counseling and financial management as waiver services and to have the costs of these services deducted from participants' budgets. See Chapter 6 for more information about methods to pay for counseling and Chapter 7 for more information about methods to pay for financial management services.

The Spending Plan

Once the budget amount is determined through the program's selected methodology, participants and their informal supports (and counselors as needed and desired) develop a plan to spend the resources allotted. This plan provides a detailed outline of how the funds will be distributed throughout the month or other designated period. Generally, participants elect to hire a personal care worker to assist them to meet their needs and spend a nominal amount on the purchase of goods and services related to their personal care needs.

States vary with regard to the items that participants may purchase with funds from their individual budget. Some allow participants to purchase only personal assistance services and supports, some allow the purchase of any service the program offers, and others allow the purchase of a wide range of services, goods, equipment, and supplies that promote participants' independence or decrease their reliance on human assistance. The §1915(j) authority specifically permits participants, at the state's option, to use their budgets to pay for items that increase their independence or substitute for human assistance, to the extent that expenditures would otherwise be made for human assistance. This is referred to as "permissible purchases" and states may make their own decisions about which items to include.

States have found it helpful to develop individual budgets using generic terms; doing so promotes flexibility. For example, rather than listing the number of personal assistance hours that are authorized, the plan specifies that the individual will receive up to a certain number of service hours or a specific dollar amount. Combining like services (e.g., respite, companion, and personal care) with a single hour or dollar maximum amount enables participants to substitute these

services for one another to meet changing needs, without having to formally change their spending plan.

Most participants use their budgets to hire an individual or individuals to assist with ADLs and IADLs. The Cash & Counseling Demonstration and Evaluation (CCDE) found considerable variation in the types of goods and services participants purchased, with specific items influenced by individual circumstances and preferences. The most frequently purchased goods and services were transportation, laundry service, homeowner’s or renter’s insurance, small kitchen appliances, small appliances in general, pharmaceutical supplies, durable medical equipment, and furniture.²⁰

The most frequently purchased “assistive technologies” were not medical devices that only people with disabilities might need or use, but rather household appliances, such as microwave ovens and washing machines. These items were especially useful to people with disabilities insofar as they enabled independent performance of certain tasks (e.g. cooking and doing laundry) that otherwise would have to be performed by an assistant.

CMS offers guidance on what it considers allowable goods and services under a §1915(c) waiver in Version 3.5 of the waiver application:

Individual Directed Goods and Services are services, equipment or supplies not otherwise provided through this waiver or through the Medicaid State Plan that address an identified need in the service plan (including improving and maintaining the participant’s opportunities for full membership in the community) and meet the following requirements: the item or service would decrease the need for other Medicaid services; AND/OR promote inclusion in the community; AND/OR increase the participant’s safety in the home environment; AND, the participant does not have the funds to purchase the item or service or the item or service is not available through another source. Individual Directed Goods and Services are purchased from the participant-directed budget. Experimental or prohibited treatments are excluded. Individual Directed Goods and Services must be documented in the service plan.²¹

Most states implementing self-direction options using Medicaid funding have adopted the CMS definition but provide more specific information and guidance to counselors and staff about allowable goods and services in their operational manuals. Some states develop and distribute pre-approved lists of items from which participants may choose. If participants select an item not identified on the approved list, states may require prior authorization for the purchase. Many states find it helpful to define goods and services using broad, generic language. For example, rather than list appliances as a covered service, the allowable list might read “devices that promote mobility and independence in the home”. Other states

have adopted a flexible approach that allows counselors to simply approve goods and services that “promote the independence of the individual.”

Some states cover services needed to prepare for and seek employment, as well as job coaching, under the budget. Idaho amended its existing §1915(c) waiver for persons with developmental disabilities to include services that assist individuals in securing and maintaining employment. Under this Idaho waiver, participants may also choose their providers of skilled services (i.e., those performed by licensed professionals, such as RNs and LPNs).

States are free to offer budgets that give participants the option to: (1) set the reimbursement rate of pay for their workers within applicable labor law and Medicaid parameters, (2) accrue savings from unspent budget amounts, and (3) participate in community activities by paying for items such as camp fees or fitness club memberships. Montana’s Big Sky Bonanza HCBS program covers culturally based services such as Native American healing rites.

States may also allow participants to pay higher rates for workers willing to work weekends and evenings. While this reduces the number of hours that can be covered, participants might, for the first time, receive needed services during these times. If programs give participants cash, policies that allow participants to accrue savings must ensure that these savings do not cause participants to lose eligibility for public benefits, including SSI or Medicaid, by exceeding asset limits.

B. Authorizing and Modifying Individual Budgets

States may grant the authority to approve purchases identified in the individual budget to one or more of the following: individual counselor, counseling supervisor, regional office staff, or central office staff. States should carefully consider which process will be the simplest and most efficient and prevent delays in commencing services. In states that require central office approval, participants have experienced delays in the commencement of services due to this centralization.

To prevent unnecessary administrative delays, many states allow that if the cost of the individual budget is equal to or less than the cost of the same services provided through the traditional service system, the counselor who has helped the participant to develop the service plan can authorize it. If the cost of the service plan exceeds the cost of the traditional service plan (or exceeds it by a specified percentage), then a supervisor or a state official must approve the budget.

States need to have a process for modifying individuals’ budgets to meet their changing needs immediately and efficiently. One strategy to ensure that this happens is to allow revisions by telephone followed by paper copy. As noted above, grouping like services or goods into categories and permitting substitutions within the subset allows a certain degree of flexibility that may preclude the need

for a formal budget modification. As noted in the discussion on spending plans, rather than list appliances as a covered item, allowable items can be defined as “devices that promote mobility and independence in the home.”

Monitoring and Managing Individual Budgets

While state agencies or offices typically have the ultimate responsibility for program oversight, most states assign responsibilities for the day-to-day management and monitoring of the individual budget to selected financial management services (FMS) entities in collaboration with counseling activities. Once the service plan has been developed and the individual budget amount determined, this information is forwarded to the FMS entity. States may employ a single FMS entity, provide FMS themselves, or give participants a choice of entities.

Basic FMS responsibilities related to managing and monitoring the individual budget include:

- Tracking the individual budget balance and associated expenditures;
- Tracking over-expenditures or under-expenditures;
- Preparing monthly budget reports for participants, listing expenditures and balances;
- Accepting invoices from providers and processing payments based on the individual budget; and
- Conducting quality assurance and consumer satisfaction surveys.

See Chapter 7 for an in-depth discussion of financial management services.

FMS entities use a variety of tracking methods to manage and monitor individual budgets. Many programs, particularly small ones, track individual budget expenditures through an off-the-shelf accounting software package. Some states, for example South Carolina, use an internal database to track expenditures. More sophisticated consulting vendors have developed their own tracking systems which include electronic versions of the individual budget. Having electronic versions makes it easier to retrieve and revise information and speeds the transfer of information between the FMS entity, counselors, and program staff. Also, see Appendix II for detailed information about the Consumer Direction Module, a computerized system for managing and monitoring individual budgets.

Resources

Publications

Agosta, J. (Spring 2004). Pointers for families and individuals who want to manage their own services. *Impact*. Volume 17(1). Minneapolis: Institute on Community Integration and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota.

This article discusses the supports individuals and families need to successfully manage their own services. Person-centered planning, individualized budgets, creative use of supports, and honoring individual wishes are discussed in detail.

Available at: <http://ici.umn.edu/products/impact/171/over4a.html>

Moseley, C.R. (Spring 2004). Individual budgeting, control and support: What systems need to tell people. *Impact*. Volume 17(1). Minneapolis: Institute on Community Integration and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota.

This article provides comprehensive information about individual budgeting, including assessing the need for support; determining an allocation amount; setting spending limits; responding to changes in support needs; and responding to appeals and requests for re-determination.

Available at: <http://ici.umn.edu/products/impact/171/over3a.html>

Moseley, C.R., Gettings, R., and Cooper, R. (2003). *Having it your Way: Understanding State Individual Budgeting Strategies*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.

This report summarizes the results of a study of methods for developing individual budgets. The study describes nine states' individual budget activities and identifies factors that are instrumental in implementing effective individual budgeting methodologies. It also provides information about approaches for transitioning from traditional program funding to individual budgeting.

An executive summary of the report is available at: <http://nasddds.org/pdf/IBExecutiveSummary.pdf>.

The full report may be purchased from NASDDDS at http://www.nasddds.org/Publications/special_pubs.shtml#understanding

Moseley, C.R. (2002). *Individual Budgeting Study: Progress Report*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.

This paper summarizes the results of a study of states' individual budgeting

strategies and includes data from additional states and an analysis of several key findings.

Available from the author at: cmoseley@nasddd.org

O'Brien, J. (2001). *Paying Customers are not Enough—The Dynamics of Individualized Funding*. Lithonia, GA: Responsive Systems Associates

This publication discusses the dynamics of individualized funding for the provision of services to people with developmental disabilities. It focuses on how individualized funding may drive the changes necessary to develop services that offer highly customized assistance.

Available offline from the Research and Training Center on Community Living at: <http://rtc.umn.edu/publications/offline.asp>. A scanned copy is available at: http://eric.ed.gov/ERICDocs/data/ericdocs2sql/content_storage_01/0000019b/80/1a/04/50.pdf

Reinhard, S., Crisp, S., and Bemis, A. (2005). *State Policy in Practice: Participant-Centered Planning and Individual Budgeting*. New Brunswick, New Jersey: Rutgers Center for State Health Policy.

This publication describes the use of person-centered planning in the development of an individual budget. The report highlights Minnesota's and New Hampshire's experience using individual budgets.

Available at: <http://www.cshp.rutgers.edu/Downloads/6810.pdf>

Spillman, B.C., Black, K.J., & Ormond, B.A. (2007). *Beyond Cash and Counseling: The Second Generation of Individual Budget-based Community Long Term Care Programs for the Elderly*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured.

This report describes 10 individual budget programs serving older persons, identifies four areas of program design that are of particular importance to the success of the individual budget model, and discusses how the states have addressed them.

Available at: <http://www.kff.org/medicaid/upload/7579.pdf>

Walker, P. (Spring 2004). *The Vermont way: Evolution of consumer-controlled budgets in Vermont*. *Impact*. Volume 17(1). Minneapolis: Institute on Community Integration and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota

Vermont's Division of Developmental Services has used individualized budgets for over 20 years. This article discusses Vermont's experiences and includes a discussion of challenges and major lessons learned.

Available at: <http://ici.umn.edu/products/impact/171/prof8a.html>

Web-Accessible Resources

Cash & Counseling National Program Office

Web-address: <http://www.cashandcounseling.org/>

This website contains wide-ranging resources concerning self-direction, including state initiatives to incorporate self-direction into the delivery of Medicaid HCBS; for example, the Scripps Gerontology Center Participant Goal Setting Tool. This tool was developed to help participants in Cash & Counseling programs set personal goals. Available at: <http://www.cashandcounseling.org/resources/20080303-130304>

Clearinghouse for Home and Community Based Services

Web-address: <http://www.hcbs.org/>

This website is the repository for wide-ranging resources concerning state efforts to expand the delivery of HCBS for people with disabilities and older persons. Self-direction is one of many topics for which resource materials are compiled and made accessible online. A number of resources about individual budgeting can be found at: <http://www.hcbs.org/advancedSearch.php> (keyword: individual budgeting)

Citations, Additional Information, and Web Addresses

- 1 Suzanne Crisp is the lead author of this chapter. Janet O’Keeffe is the co-author.
- 2 Different programs (e.g., Medicaid and those funded solely by the states) and even different benefits within programs (e.g., Medicaid State Plan or waiver benefits) vary in how they define the types of needs that participants may use their funds to meet. Some focus narrowly on “medical” needs; others encompass a broader range of disability support needs, including, for example, needs related to employment.
- 3 The consensus has been largely derived from the research and experiences of the National Association of State Directors of Developmental Disabilities Services, the Cash & Counseling Demonstration and Evaluation (CCDE), and the Centers for Medicare & Medicaid Services (CMS).
- 4 Agosta, J. (Spring 2004). Pointers for families and individuals who want to manage their own services. *Impact*. Volume 17(1). Minneapolis: Institute on Community Integration and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota. See Resources section for a link to this article.
- 5 Moseley, C. (Spring 2004). Individual budgeting, control and support: What systems need to tell people. *Impact*. Volume 17(1). Minneapolis: Institute on Community Integration and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota. See Resources section for a link to this article.
- 6 Moseley, C., Gettings, R.M., and Cooper, R. (2003). *Having It Your Way, Understanding State Individual Budget Strategies*. National Association of State Directors of Developmental Disabilities Services, Inc. <http://tcds.edb.utexas.edu/TSDPT/IndividBudgets.htm>
- 7 Smull, M., *An Overview of Essential Lifestyle Planning*. (1996). <http://www.allenshea.com/brochure.pdf>
- 8 CMS State Medicaid Director Letters: Optional Self-Direction Personal Assistance Services Program, 09/13/2007. Available at www.hcbs.org/moreInfo.php/doc/2038
 Medicaid Program; Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling); Proposed Rule January 18, 2008. Available at <http://edocket.access.gpo.gov/2008/pdf/08-115.pdf>
- 9 Application for a §1915(c) Home and Community-Based Waiver, Version 3.5, Instructions, Technical Guide, January, 2008. Page 305. Available at: <https://www.hcbswaivers.net/CMS/faces/portal.jsp>

- 10 Reinhard, S., Crisp, S., and Bemis, A. (2005). *Participant-Centered Planning and Individual Budgeting*. New Brunswick, New Jersey: Rutgers Center for State Health Policy. See Resource Section for a link to this article.
- 11 Activities of daily living (ADLs) include eating, bathing, dressing, toileting, transferring, grooming, and maintaining continence; instrumental activities of daily living (IADLs) include medication management, light housework, laundry, meal preparation, transportation, and grocery shopping.
- 12 Moseley, C., Gettings, R.M., and Cooper, R. (2003). Op. cit.
- 13 This Handbook uses the term service plan. States vary in their use of terms for this activity, for example, care planning, support planning, or recovery planning (for individuals with serious mental illness).
- 14 Application for a §1915(c) Home and Community-Based Waiver, Version 3.5, Instructions, Technical Guide, January, 2008. Page 178. Available at: <https://www.hcbswaivers.net/CMS/faces/portal.jsp>
- 15 §1915(c) waivers must be cost neutral (i.e., the cost of waiver services can not exceed the cost of institutional services). While there is no federal requirement that self-direction programs be cost-neutral relative to traditional service delivery program, when introducing a new self-direction program, state legislatures and budget offices often want assurances that the new self-direction program will be cost-neutral (i.e., not cost more than the state is currently paying for the traditional service delivery system).
- 16 Campbell, E.M., Fortune, J., Frisch, J.K., Heal, L.W., Heinlein, K.B., Lynch, R.M., Severance, D.D. (2004). Predictors of expenditures in Western states. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and Outcomes of Community Services for People with Intellectual Disabilities*. Baltimore: Paul H. Brookes Publishing.
- 17 MN Department of Human Services, Disability Services Division, MR/RC Waiver, Consumer-Directed Services Budget Formula. Available at http://www.dhs.state.mn.us/main/groups/disabilities/documents/pub/dhs_id_029336.pdf
- 18 B Campbell, E.M., Fortune, J., Frisch, J.K., Heal, L.W., Heinlein, K.B., Lynch, R.M., & Severance, D.D. (2004). Op. cit.
- 19 In 2003, the majority of the C&C Replication states selected Section (§) 1915(c) HCBS waivers as the Medicaid authority for developing their self-direction programs. Federal Medicaid rules require HCBS waiver programs to be cost-neutral (i.e., the cost of waiver services can not exceed the cost of institutionalization). States have the option of meeting this requirement using per capita costs or aggregate waiver costs, the latter approach providing more

flexibility. The C&C Demonstration and Evaluation (CCDE) states had to meet the budget neutrality requirement of §1115 research and demonstration waivers, which require that federal expenditures for the demonstration cannot exceed federal expenditures without the demonstration.

An early analysis of service plans compared to services delivered revealed that participants in Arkansas and New Jersey were not receiving their authorized hours under the traditional agency-delivered service model due to limited provider capacity. For example, in Arkansas, in the first year of the demonstration program, more than one-quarter of those authorized to receive agency services failed to receive *any* paid personal assistance services, and those who did, as a group, received only 68 percent of authorized hours. In contrast, virtually all CCDE participants (97 percent) reported receiving paid services. Similarly, in New Jersey, approximately 11 percent of participants served in the traditional systems did not receive any paid services compared to only 4 percent of CCDE participants.

The provision of authorized personal assistance increased under the demonstration program because participants were able to select their own workers. As a result, costs for the demonstration program were higher than under the traditional program that used agency workers. To maintain budget neutrality, states began to quantify the shortfall in the delivery of authorized services and to discount individual budgets to reflect this difference. For example, Arkansas reduced all individual budgets by 10 percent.

- 20 Renter's and homeowner's insurance can provide some financial protection in the event a worker not covered by workers compensation insurance is injured while in the home. However, filing a claim can lead to loss of coverage, which could be a major problem if an individual has a mortgage that requires insurance coverage. See Chapter 7 for a discussion of workers compensation insurance.
- 21 The Centers for Medicare & Medicaid Services, §1915(c) Home and Community-Based Waiver Application Version 3.5. Available at: <https://www.hcbswaivers.net/CMS/faces/portal.jsp>