



MAKING SELF-DIRECTION A REALITY:

Using Individual
Budgets to Promote
Choice, Control,
and Equity



Human Services
Research Institute



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Using Individual Budgets to Promote Choice, Control, and Equity

Self-direction is a fast-growing platform for the delivery of community-based services and supports to people who need long-term care, and many states are choosing to use individual budgeting to make it a reality. Basing budget amounts on assessed need can help ensure that people have equal access to services across a service population. To better understand the methods that states use to create individual budgets, the benefits and risks of these approaches, and their level of alignment with principles of self-determination, we examined 260 1915(c) Home and Community-Based Service waivers from across the nation.

BY JAMI PETNER-ARREY, YOSHI KARDELL, AND COLLEEN KIDNEY

Long-term services and supports (LTSS) play a vital role in helping to meet the basic needs of many people with disabilities, and self-direction is a fast-growing platform¹ for the delivery of community-based LTSS. Self-direction gives people the authority to select and purchase—based on their service plan and from providers they choose—the supports and services that best suit their needs and life goals. A growing body of evidence shows

that self-direction is associated with positive outcomes,² and policymakers and public funders are looking to redesign systems to support such person-centered practices. At the same time, policymakers must strike a delicate balance between assuring that people receive the support they need to live a full life in the community and the reality of working within the constraints of the overall state budget.



31 states
are using assessment-
informed budgets
to distribute HCBS
waiver funds

¹ Edwards-Orr, N. & Ujvari, K. (2018). Taking it to the next level: Using innovative strategies to expand self-direction. Published by AARP Public Policy Institute. Retrieved from: http://longtermscorecard.org/~media/AARP1122_PP_SelfDirection_WEB.pdf

² Bradley, V. & Li, H. (2019). Self-direction: Are we there yet? A brief status report from the US and beyond. Presented at Applied Self-Direction National Conference. Retrieved from: <http://www.appliedselfdirection.com/resources/self-direction-are-we-there-yet>.

Several circumstances make this an ideal time for states to redesign systems to equitably support self-direction:

✱ **The Home and Community-Based Services (HCBS)**

Settings Rule, released by the Centers for Medicare & Medicaid Services (CMS) in January 2014, aims to ensure that Medicaid-funded HCBS programs “provide people with disabilities opportunities to live, work, and receive services in integrated, community settings where they can fully engage in community life.”³ It also includes expectations for person-centered planning: an approach directed by the person and geared around their needs, preferences, and goals.⁴ Nearly all states offer services through Medicaid HCBS Waivers. (In fact, there are more than 300 HCBS Waiver programs active nationwide.) And states have until March 2022 to come into compliance with the Settings Rule.

✱ **The service landscape is changing.** Demand for custodial services has shifted. Services are now expected to expand independence and choice. While many people with disabilities



26% increase
Total state and federal expenditures for section 1915(c) waiver programs increased 26% from FY11 to FY16.⁵

require support of some kind, formal services may be only partially successful in getting people what they truly want—such as meaningful connections with others and full access to the community just as any other citizen. At times, formal services can create unintended barriers.

✱ **Available resources do not match demand for services.** State budgets are limited and must be spread among a number of populations that require support—and some of these populations are expected to increase in coming decades.⁶ The aging of the US population and prevalence of chronic health

conditions is expected to substantially increase the number of people with disabilities, along with the demand, use, and cost for personal health services and LTSS.⁷ Moreover, with changing social and socioeconomic trends, there are likely to be fewer people who can fill the role of informal caregivers, providing uncompensated LTSS.⁸

Given these factors, policymakers must decide very strategically how to best structure waiver programs in order to achieve valued outcomes.

Transitioning to Individual Budgets

Some states are implementing “prospective” individual budgets for service users—meaning the amount of the budget is made known to the person prior to any service planning meeting. Ideally, the individual can determine how best to spend their budget by deciding, with their support network, which services and supports best meet their needs. Prospective budgets also help the state manage and predict costs.

³ <https://www.thearc.org/document.doc?id=5429>

⁴ Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers, Fed. Reg. 00487 (Jan. 16, 2014). Retrieved from: <https://www.federalregister.gov/documents/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>

⁵ Medicaid Expenditures for Section 1915(c) Home and Community-Based Services Waiver Programs in FY 2016 (August 2018). Retrieved from: <https://www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/1915c-expenditures-fy2016.pdf>

⁶ Osterman, P. (2017). Who Will Care for Us? Long-Term Care and the Long-Term Workforce. New York: Russel Sage Foundation.

⁷ Thach, N.T. & Wiener, J. (2018). An Overview Of Long-Term Services And Supports And Medicaid: Final Report. Retrieved from: <https://aspe.hhs.gov/system/files/pdf/259521/LTSSMedicaid.pdf>

⁸ Ibid.

THE PROCESS OF DEVELOPING AN ASSESSMENT-INFORMED BUDGET



One of the core benefits of using assessment-informed budgets is that they can be objectively applied to individuals with varying support needs, fostering equitable services across a state.

As states transition to these approaches, people with disabilities, their families, and providers are calling for fair and transparent budgeting practices with sound methodologies. To achieve this, states are increasingly adopting assessment-informed budgets. An assessment-informed budget uses a standardized assessment tool that measures the support a person needs to engage in daily activities like

eating, maintaining hygiene, or shopping. The assessment is likely used in combination with a review of personal characteristics such as living setting to determine a person's need and to calculate a budget prior to the individual's planning meeting. The budget is the amount of funding the person has available to spend, and it guides service planning within the context of a broader conversation about overall goals, support needs, and strengths.

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In our review of 260 1915(c) HCBS waivers, we found that the majority of states—31 states—were using assessment-informed budgets for at least one LTSS population. In fact, these approaches were used across a total of 41 HCBS waiv-

ers, meaning that some states used assessment-informed budgets to serve several populations.

Importantly, assessment-informed budgets are not composed by selecting needed services during or prior to planning and adding the cost of the services together. Though this method is commonly used to determine budgets in LTSS, it is not the focus of this paper.

In terms of the standardized assessments used to generate budget amounts, several states use state-specific assessment tools (MnCHOICES in Minnesota, MONA in Montana, QSI in Florida, NJCAT in New Jersey, etc.). Other states use assessments intended for national or international use like the Inventory for Client and Agency Planning (ICAP) or the Supports Intensity Scale (SIS®). Typically, assessments are combined with other variables that affect cost of services (e.g., living setting).

We classified state approaches into two categories: individually tailored approaches that result in a unique budget for each individual, and level-based approaches where funding ‘tiers’—or levels—are assigned to individuals with similar needs and are associated with a particular budget amount. Examples of both are presented here. Overall, level-based approaches were most common and were being used by 74% of the waivers we reviewed.

Notably though, even within the same category, approaches vary considerably in the way they are developed and implemented, likely due to circumstances unique to each state. Some states may require that the budget is used to purchase all services while other states may offer a budget for only a handful of services. Legislative or court mandates, public opinion and advocacy, readiness for change, and available resources may also affect the approach.

Example of a Level-Based Approach

As an example, one state’s developmental disabilities department uses a level-based approach in its HCBS waiver to produce budgets for service recipients. Scores from a state-specific assessment tool are used to assign each person to a tier that is associated with a budget amount and specific rates for services. There are five tiers based on support need alone, and five tiers for people with behavioral needs.

Budgets are used to purchase a range of paid services, including day and employment supports, individual and family supports, in-home and residential supports, and supported employment (as needed). There is some ability to move money between and among services within the total budget. An additional supported employment amount can be requested when the budget is insufficient to support continued employment.



Level-based are widely used

¾ of the 1915(c) HCBS waivers reviewed use level-based budgets

As with all level-based approaches, everyone within a specific tier has the same budget amount. The person is notified of their tier assignment within a month of the assessment, and that information is used to guide service planning. The assessment recurs every five years, but substantial changes to a person’s needs can prompt an earlier reassessment.

AN EXAMPLE OF A LEVEL-BASED BUDGET

TIER	EMPLOYMENT/ DAY SUPPORTS	INDIVIDUAL/ FAMILY SUPPORTS	IN-HOME/ RESIDENTIAL	TOTAL BUDGET
A	\$10,000	\$5,000	\$20,000	\$35,000
A-behavioral	\$15,000	\$5,000	\$30,000	\$50,000
B	\$15,000	\$5,000	\$35,000	\$55,000
B-behavioral	\$20,000	\$10,000	\$50,000	\$80,000
C	\$20,000	\$10,000	\$60,000	\$90,000
C-behavioral	\$30,000	\$10,000	\$70,000	\$110,000
D	\$30,000	\$15,000	\$80,000	\$125,000
D-behavioral	\$40,000	\$15,000	\$90,000	\$145,000
E	\$40,000	\$20,000	\$90,000	\$150,000
E-behavioral	\$40,000	\$20,000	\$100,000	\$160,000

EXAMPLE ELEMENTS OF AN ALGORITHM FOR AN INDIVIDUALLY TAILORED APPROACH

DESCRIPTION	WEIGHT
Independent Living	34.5550
Residential Support	91.5294
Behavioral Needs	97.7008
Intensive Behavioral Need	149.4098
Home Medical Needs	208.9099
Child under 18	46.7664
Adult over 18	50.1234
Eating	2.0884
Self-Care	8.6457
Grooming	6.6678
Self-protection	6.3555
Aggression	3.8864
Specialized Medical	2.8444

Example of an Individually Tailored Approach

A state developmental disabilities department uses an individually tailored approach for its HCBS waiver serving individuals with a range of disabilities. To receive a budget, each service recipient participates in a state-specific assessment. Age, living setting, and weighted scores from the assessment are used to calculate the initial budget for each individual. Additional factors are then added in to compose the final budget. This budget equation is determined by analysis of the relationship between support need and other factors to historical costs. After the department has reviewed all materials related to the budget and service plan, they approve the final budget. If the person needs more services than their

funding allows, they can demonstrate that they have significant additional needs or request a fair hearing. Individuals can also request a new assessment if their situation changes.

The graphic on the left presents some elements of an algorithm used to produce the individually tailored budgets like the one described. The score on each variable is multiplied by its weight, then all are added together for the initial budget (prior to adding additional factors).

Getting the Budget Right

No matter the approach used, states must be able to implement budgets fairly and equitably across a large service population. Therefore, the chosen approach cannot be so complicated that it is difficult for state staff to implement or manage—or so individualized that it offers little to no efficiencies for the state. Each state must strike a balance between achieving its goals for promoting self-direction and maintaining sustainability.

Because individuals often rely on personal budgets to meet their critical support needs, the methods used to formulate budgets are subject to intense scrutiny. Approaches must use sound statistical methods or other evidence to explain how and why the budget is calculated the way it is. The same applies to assessments; the assessment tool must be valid and reliable.

While assessments offer a way of objectively measuring need, no single assessment can capture every person's unique support needs. There are often other factors apart from the assessment (age, for example) that affect support needs and that should be taken into account. While some approaches are based on only a handful of assessment items, broader combinations of items have the potential to present a more holistic picture of the person's support needs. Furthermore, behavioral and medical needs remain difficult to capture in assessments. Many assessments address medical diagnoses that may have little bearing on the person's support needs; for example, if the person is able to completely comply



Key factors for assessment-informed budgets

- * Sound statistical methods, articulable to stakeholders
- * Valid and reliable assessments with strong psychometric properties
- * Consideration of additional measures
- * Collection and analysis of comprehensive and accurate data
- * Sustainable model

Clearly articulated policies and open channels for exchanging information with people who use services have the added benefit of encouraging self-direction.

with treatments independently, they may not need support for the diagnosis. Similarly, while known behavioral incidents are frequently recorded on assessments (e.g., how often a person uses physical aggression), it is challenging to account for behavioral needs that are episodic but intense.

Since the assessment is the foundation of the budget, careful attention should be paid to ensure that the assessment has strong psychometric properties. Sometimes additional measures are necessary to supplement the assessment in order to improve the accuracy of the resulting budget and account for needs not measured in the assessment.

Combining comprehensive data sources

Once a valid and reliable assessment process is in place, states begin the arduous process of collecting data. Data should be collected from many sources in addition to the assessment—including individual service use and spending. Combining these comprehensive data sources can present a picture of the state's needs and offer ideas about how best to structure the approach. For instance, a state can conduct multiple analyses to determine which living settings have meaningful differences in service use to determine how living setting

should factor into the budget calculation.

States may struggle merging data sources in a way that is most useful since data may be housed in a variety of systems. The quality of the available data must be carefully assessed, and every effort must be made to ensure the integrity of data. In addition, the approach must be grounded in strong statistical methods and reasoning—but it must also be understandable to the general public so it can be shared with people with disabilities and their support networks.

All budget approaches will need to be adjusted in some way over

time. Service costs change, new services are added, and old services terminate, requiring states to adjust personal budgets. To be sustainable, approaches must be developed in a way that allows thoughtful and necessary changes to be implemented when necessary.

Managing System Change

As with any systemic change of this magnitude, it's important to limit disruptions to people who depend on services. Minimizing impacts to service recipients supports confidence in the budget but should not come at the price of innovation.

Usually the goals that are driving the adoption of individualized budgets make these large-scale changes worthwhile, but it's important to support people who



depend on this funding to have confidence that they can access their budget reliably from year to year. In this regard, states may choose sustainable approaches that can be altered over time. For example, many states that use a level-based approach have the benefit of being able to adjust the budget to account for changes (e.g., if a rate for a service changes, the budget can be altered to reflect the change in rates); since individually tailored budgets are often directly tied to past spending, any change requires a change to the entire analysis, algorithm, and budgets when new spending data is added. Another way that states limit disruption is by phasing people into a new budget when changes are inevitable. This might mean that someone whose budget will be reduced may have a year or more before they experience the full impact of the reduction.

Communicating policies and procedures

Policies and procedures should be clearly articulated and well-known to ensure that budgets are objectively applied. Good communication is first and foremost for the benefit of people with disabilities and their support networks. Individual

Many states are using individual budgets to address disparities and to bring equity to the service population

budgets may also be contested in courts, as has been the case for several states that have gone this route. For these reasons, it's imperative that states consider not only their efforts to make information available but also their legal obligations to people who use services. Clearly articulated policies and open channels for exchanging information with people who use services have the added benefit of encouraging self-direction.

Planning for exceptions

No approach can yield perfect results. There will always be some number of people with needs that extend beyond the boundaries of the budget. All assessment-informed budgets should have robust procedures for allowing people to request additional funding if the budget is insufficient to meet their needs—procedures that can be objectively evaluated. Ideally these procedures occur before formal appeal or grievance processes and are easier for people with disabilities to navigate. In this way, budgets can flexibly support people with needs that are not easily measured.

Values-Driven Change

Prior to implementing an individual budget approach, many states come to understand that there are wide discrepancies in how people use services, even among people with similar support needs. This might result in people with few support needs receiving the maximum amount of services and people with high

support needs receiving few services. Additionally, geographic differences might exist that have little to do with what people request (e.g., rural areas may have fewer services available). Individual budgets provide an opportunity to at least offer the same baseline budget to people who have similar needs and to level the playing field. In this way many states are using budgets to address disparities between service recipients and to bring equity to the service population. Similarly, having an expectation about the types and amounts of services that people are likely to need can help a state assess how well it's meeting the needs of people who depend on services. Comparing support needs with outcome data can strengthen a state's understanding of which services might lead to desired outcomes, like employment, for people with a range of support needs.

Using a LifeCourse Lens

When a state is embarking on an assessment-informed budget approach, it's crucial for the state to clearly articulate its goals and expectations for the change. Doing so will help the state to decide how to address the multitude of questions that arise. One way that states might facilitate a move in the right direction is to use a guiding framework to structure the development. Charting the LifeCourse (CtLC; <https://www.lifecoursetools.com/>) is a recently developed structure for planning supports to people with disabilities. It ensures that a range of community, individual, technology and

Finally, to truly give people with disabilities the power to control their supports and services, people with disabilities need to be in the driver's seat.

policy factors are considered when thinking about how to support people in achieving their desired life goals. Using a CtLC framework can help states to set guideposts for desired outcomes and to ensure that at each point in the development and implementation of an individual budget approach, the state is still moving in the desired direction.

Involving the People Who Matter Most

Just as people with disabilities are asking for opportunities to direct their supports and services, they are also calling for more opportunities to help structure the systems that support them—or, at a minimum, to know more about the systems they rely on. States should be prepared to include people with disabilities in conversations about individual budgets from start to finish—from the time the approach is first considered through well beyond implementation.

Early on when a state is considering developing an individual budget model, the state should be prepared to take stock of what people with disabilities and their families are seeking. Often, states use this transition

as a time to make other needed changes (e.g., updating service arrays to make sure services are ample and can meet the varying needs of people with disabilities). Since these changes will impact service recipients, it will be important for state staff to hear from people with disabilities about the best way to ensure a successful transition and the sorts of problems the changes might bring about. Keeping people who use services involved early and often is key.

Some states have elected to include people with disabilities, their families, and other stakeholders in the actual development of the individual budgets.⁹ States have included individuals who have helped with everything from analysis activities to naming elements of the budget. This involvement may inform policy-makers of stakeholders' unique insights into the feasibility and limitations of the approach, as well as the best ways to increase understanding and utility of communication efforts.

Beyond lip-service: Promoting control for individuals and families

While there are different methods for arriving at assessment-informed budgets, there

are several key factors that must be in place for the process to deliver on the expectation of more choice and control for the end-user. Without due attention to this aim, the promise of providing authority over a budget is hollow. For individual budgets to be aligned with principles of self-determination, people with disabilities and their support networks must:

- Know their budget amount ahead of their service planning meeting
- Be educated about what their budget means
- Have technology and support available to use their budget
- Have the authority to make decisions about what best meets their needs

The key to operationalizing this comes down to robust service planning practices—including training, mentoring, and modeling for case managers/support coordinators who are responsible for assisting people with service planning processes. They need to have the information and skills to guide service recipients to use their budgets to plan for needed support—including other sources of support like those based on relationships with natural supports so that people with disabilities aren't cocooned in services. Case managers need to educate people with disabilities about what it means to plan with a budget.

Many state systems have inward-facing technology appli-

⁹ <https://edocs.dhs.state.mn.us/lfserver/Public/DHS-7841A-ENG>

cations to help them compute the budget and tally services that can be purchased using the budget. To support people with disabilities and their families to have the same capacity to understand how their budgets can be applied, states may need to consider outward-facing technological solutions that provide information about services and how much they cost. They may also need support to use any technological solutions (e.g., training, tutorials).

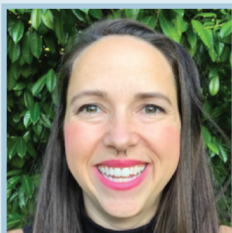
When individualized budgets are implemented, some individuals

may experience a reduction in their budget and have fewer funds available to them than in the previous year. This often means that individuals have to make do with fewer services. To support people through this transition, states need to be able to show people how they can leverage other supports—including their support networks, generic supports available to the general public, and community supports.

Finally, to truly give people with disabilities the power to control their supports and services,

people with disabilities need to be in the driver's seat. They need to be able to make choices about how and when they want to be supported and by whom. Most importantly, those decisions must be upheld to the extent that is reasonable and safe for the person. People with disabilities have unique strengths and talents, as we all do, and those strengths need to be built upon and expanded so that they can control not only the services they receive but also their lives.

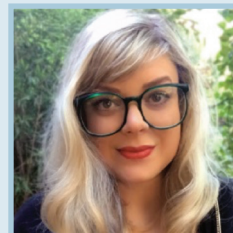
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