

Building Personal Supports Budgets for Adults with Intellectual/Developmental Disabilities

Information Brief

Person-centered Planning and Supports Budgets

November 27, 2015

People with intellectual and developmental disabilities (IDD) want to live, love, work, play, and pursue their life aspirations, just as others do in their community. Yet to do so, they often need support provided by family or friends, community organizations, businesses or through publicly funded services.

Increasingly, person-centered principles drive the supports planning processes.¹ These principles and associated approaches provide an opportunity for each person with IDD to explore their dreams, objectives, and support needs. The result of this process should be a plan that meets the goals and needs of each individual and that addresses what is important “to” the person by way of his or her preferences, and “for” the individual to remain safe and healthy.²

Often, this planning process unfolds without discussion of the precise public funding available to purchase needed support. Only later, and many times in a separate process, is funding approved or modified. A better way is to identify a personal *supports budget* for each service recipient in advance of supports planning so that the process is informed by realistic expectations for funding.

The purpose of this Information Brief is to describe the person-centered planning and supports budgeting processes, and illustrate how the two may be integrated. By doing so, the goals of community integration and self-determination for individuals with IDD and their families are more likely to be realized.

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¹ In the United States in 2014 qualifications for a person-centered planning process are defined by a rule issued by the primary federal funding agency for IDD services, Medicaid. The rule is directed at services delivered through the Home and Community Based Services (HCBS) waiver authority. Learn more at <http://www.medicaid.gov>, or from a variety of sources on the web (e.g., www.nasddd.org).

² The ideas of considering “what is important to and for a person” and realities of a “paid service life” are attributed in this Brief to Michael Smull and the Essential Lifestyle Planning process (<http://sdaus.com/>)



What is person-centered planning?

There is no single definition of **person-centered planning**, although there are widely accepted principles associated with such planning. Generally, *person-centered planning* is

a process directed by the person for whom the plan is for, resulting in a summary of the individual's dreams, aspirations, goals and support needs as well a description of the services and supports that will be provided in response

While the process centers on the person with IDD, it also commonly involves a planning facilitator and members of the person's circle of support who consider the individual's dreams, objectives, and day-to-day support needs, as well as their connections with family and community. The purpose of the plan is to identify the services and supports that will further individual preferences, taking into account what is important *to* the person, and also *for* the person to live a healthy and safe life.

Some of the common person-centered planning tools include MAPS- Making Action Plans, PATH- Planning Alternative Tomorrows with Hope, Essential Lifestyle Planning, and Personal Futures Planning. LifeCourse principles consider support needs based on the individual's life trajectory and sources of potential support and may also help guide planning. All of these tools employ different information gathering strategies, but are similar in their focus on individual strengths and desires.



What are the benefits of person-centered planning?

In the past, planning for supports with public services largely focused on establishing goals and objectives related to specific learning objectives (e.g., taking a shower, preparing a meal) or daily support needs. The resulting interventions may well have strengthened life skills, but also tended to promote a focus on public services while diminishing emphasis on more general life goals and related

preferences of individuals. This often resulted in a narrowly focused service plan that left individuals leading a paid service life (credit: Michael Smull).

Today, person-centered planning practices ensure that the values and goals of the individual drive the planning process.



Through discussion with the individual and others close to him or her, a planner may identify:

- *Aspirational goals* to reflect longer term intentions, such as marriage, taking a tropical vacation, or more immediate goals that fall outside a typical week routine.
- *Learning or skill building objectives* to specify particular skills that the person decides to learn.
- *Community participation activities* to indicate regular activities that the individual joins in.
- *Day-to-day support needs* to specify the supports a person needs daily.

As a result, the discussion process results in a plan that is unique to each person and incorporates the full spectrum of supports available to that person.

If the intent of public policy for people with IDD is to offer the opportunity to live, love, work, play, and pursue life aspirations as others do, then person-centered planning practices is a means to deliver on that promise.



What is a supports budget?

A **supports budget** is a targeted amount of money, or allocation that is available to individual service recipients to acquire the services they need and prefer. The amount is determined by assessing the extent of an individual's support needs, while accounting for where they live (e.g., community residence, family), and their age (e.g., youth or adult). An *exceptions review process* must also be used to assure that extraordinary needs are appropriately addressed.

An objective assessment, such as the Supports Intensity Scale® (SIS) (<http://aaidd.org/sis>), is an important part of the supports budgeting process because it provides information about a person’s support needs. This information is used to assign an individual to a *support level* that indicates the intensity of the individual’s needs.

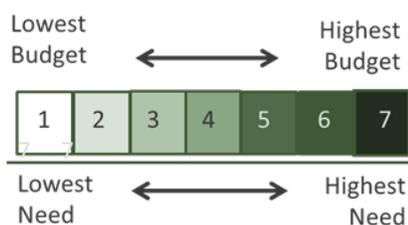
Support levels in each jurisdiction are established using assessment score criteria. Once an assessment is completed, individuals are assigned to the supports level which corresponds to their assessment score.

Policy makers and others also decide on the type and amount of commonly used paid services that should be associated with each level. A supports budget is then calculated for each level based on a known reimbursement schedule for services. The amount per level may be a fixed amount, though policy makers may instead establish an acceptable range or “budget band” for each level.

Note that supports budget accounts for commonly used services, such as residential, day, or “in-home” supports. Other unique services, such as therapies or assistive technology, may be added on to the budget on a person-by-person basis.

When applied, the individual and/or guardian learn about the assigned level and supports budget before the service planning meeting. At the meeting, the anticipated service use pattern that defines a particular supports budget acts as a guide and is not meant to be a rigid template for a particular service recipient. Individuals may alter this pattern according to their preferences as long as they stay within their budget. The plans developed in these meetings are then submitted for review by the funding authority. An exceptions review may be called for if additional resources are thought to be required.

The accompanying graphic displays a typical seven level framework. Level 1 represents least support needs and Level 7 represent most support needs.



The graphic shows that different support levels correspond to funding amounts (supports budgets) that are tiered so that people can acquire services responsive to their needs.

While there are variations in this framework, this approach helps ensure that resources are distributed in a consistent and fair manner and that individuals get the support they need— no more and no less.



What are the benefits of supports budgets?

As promising as traditional person centered planning practices are for addressing personal needs, these practices are not well suited on their own for achieving larger systems-related goals.

“As the prime determinant of an allocation, [person-centered planning] lacks the precision needed by policy-makers and funders who have the fiscal obligation to manage finite appropriations for services...”

There is a marked tendency for strong families and advocates to utilize person-centered planning effectively, while those without this good fortune often fail to garner similar supports and resources.

It is unrealistic to suppose that the attainment of personal goals, on a highly individual basis, can serve as the sole foundation for allocating scarce resources.”

Tom Nerney (2001) *Filthy Lucre*

In this context, supports budgets introduce a number of benefits.

At the systems level, supports budgets allow policy makers to structure the service system in ways that are transparent, predictable and fair, and that provide individuals with publicly funded services commensurate to their needs. Policy intentions regarding inclusion and self-direction may also be advanced through the services offered.

At the individual level, supports budgets assure that individuals know what their allocation is in advance of planning, so that they can choose the type and amount of services in their plan. Knowing one’s

budget promotes self-determination by putting people in charge of identifying the services they receive from the outset.

This perspective is consistent with approaches that emphasize supported decision-making.

Supported decision-making is a way people can make their own decisions and stay in charge of their lives, while receiving any help they need to do so.

<http://supporteddecisionmaking.org/>

The challenge to individuals in a person-centered planning meeting is to enlist help from their circle of support to make informed decisions about how their supports budget is applied.

From these perspectives, supports budgets complete the person-centered process by:



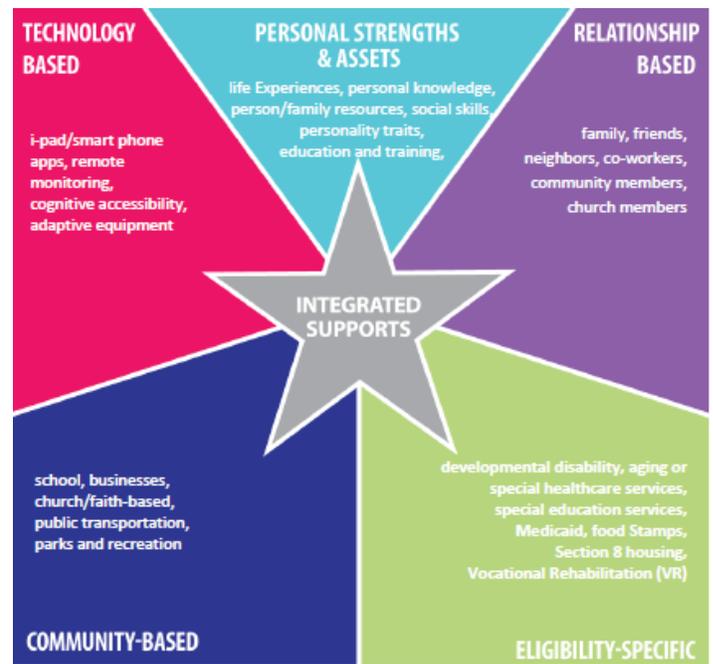
- Assuming that people with IDD should take an active role in every part of their service planning process, including knowing how to direct the use of a supports budget that may be applied to receive needed support, and
- Advancing efforts to blend together best intentions regarding self-direction and community integration with the need for fiscal discipline and fairness in public policy.



How is a supports budget included in the planning process?

To begin, individuals are typically notified by letter of their level assignment and their associated supports budget. How far in advance of supports planning the individual is notified varies by jurisdiction.

With such information, a person-centered planning process unfolds much as it always has. Discussion focuses on the individual, so that goals and objectives are established, while developing an understanding of the individual’s day-to-day support needs.



Source: <http://supportstofamilies.org/>

Knowing the supports budget ahead of time creates the space for a productive discussion between the individual and the planning team about the full range of supports, paid and unpaid, that are available to address the person’s needs. These include:

- *Personal self-support* - when a person is on his or her own and without assistance from others.
- *Relational Supports*- for when the individual receives support from family or friends.
- *Paid eligibility specific* - IDD services that are provided to the individual through the supports budget and other services that are added on (e.g., personal assistance, day services, assistive technology).
- *Community based supports* provided by community serving organizations, businesses, or other public services the person may use.
- *Technology based support* - for times when the individual can be supported by technology instead of staff supports.

The planning meeting creates an “integrated supports plan” that illustrates the range of paid and unpaid supports that will be applied to address the person’s identified needs. It is anticipated that the service costs will fall within the supports budget.



What does this mean for me?

How services are delivered is just as important as *what* is offered. The most effective services occur when the person receiving services is as in charge of their services as possible.

While practices associated with person-centered planning afford people an opportunity to shape supports to their needs and preferences, a supports budget adds value by giving people knowledge of their allocation in advance of supports planning. Understanding what they may spend empowers the individual to choose services that are most helpful and important to them.

Knowledge of a supports budget, however, changes the planning process and requires new actions from all involved.



For individuals with IDD,

knowing your supports budget means that you will now have greater control over the supports you receive. It also means that you will have greater responsibility to make decisions about what you need to be safe, healthy, and to pursue your goals. If you need help to make decisions, ask for it! But know that more than ever, you have an opportunity to be in charge of your life.

Similarly, **for families** of people with IDD, the introduction of supports budgets to the planning process brings opportunity and responsibility. You should be prepared to help your loved one to understand their budget, identify different choices they may make in selecting both paid and unpaid supports to meet their needs, and to support the decisions they make. In this regard, it is understood that a balance must sometimes be struck between supporting the decisions of a loved one while accounting for their health and well-being.

For case managers, you will now have greater opportunity to help the individuals you support take charge of their lives. You will help individuals create an integrated supports plan that balances individual goals and demands for services, within a pre-set

budget amount for paid services. Like always, this plan must assure the health and well-being of the individual.

This may lead you to develop and offer opportunities for unpaid supports to complete a successful plan. You may also need to help people seek additional paid services as needed.

For providers, effective use of supports budgets will encourage a shift from a supply-centered system to one that is more responsive to individual preferences. The most successful providers will be those that deliver high quality services that address the needs of the present and coming generation of service recipients, while being agile enough to shift their approaches to accommodate a more demand-centered system.

As a result, providers should be prepared to attend planning meetings to explore individual aspirations and support needs, and to help build integrated support plans where the paid services delivered by providers work in harmony with other types of supports the person receives.

These shifts, while consistent with increasing demands for self-direction, inclusion, and varied community options, may require providers to reconsider their present business models.

For policy makers, applying a supports budgets framework helps to ensure that funds are allocated fairly and purposively, and in ways that encourage self-direction. Policy makers, however, also carry responsibility for developing and supporting the infrastructure needed for success. For instance: policy makers must assure that:

- The array of public services available to people with IDD is consistent with progressive ideals related to community integration, and that rates of service reimbursement are fair and ample.
- People with IDD and families receive information and training so that they can play empowered roles during planning meetings.

- Case managers receive training and support to understand how to manage a planning meeting with a supports budget known to participants.
- Providers may need support to adjust their business models to accommodate shifting service preferences.



Where can I learn more?

Many individuals have contributed to the literature regarding various means of undertaking a person-centered planning process. To learn more, a good place to start is to identify information on the topic made available by your local IDD service agency.

Chances are that this agency already has developed or gathered materials on person-centered planning for you to review. More generally, you might search the internet for materials. Use the following keywords to guide your search:

Essential Lifestyle Planning (ELP)
 LifeCourse toolkits (supports to families)
 Making Action Plans (MAPs)
 Personal Futures Planning
 Planning Alternative Tomorrows with Hope (PATH)

Information pertaining to supports budgets is more recently available with selected references as follows:

Agosta, J., Fortune, J., Kimmich, M., Melda, K. & Smith, D. (2009) *Using Individual Budget Allocations to Support People with Intellectual and Developmental Disabilities*. Tualatin, OR: Human Services Research Institute.

Agosta, J., Petner-Arrey, J., Aiken, F., Kardell, Y., Rojas, R., Taylor, B., Vazquez, A., & Villwok, M. (2015) *Building Personal Supports Budgets for Adults with Intellectual/Developmental Disabilities: Supports Intensity Scale and Assessment Levels*. Tualatin, OR: Human Services Research Institute.

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Attention!

New Rules for Person-Centered Planning in the United States

In March 2014 the Centers for Medicare and Medicaid Services (CMS) issued new requirements regarding the delivery of Home and Community Based Services (HCBS). These rules emphasize community integration, person-centered planning and services, and choice, including self-direction. For example, the National Association of Directors of Developmental Disabilities Services (www.nasdds.org) advises that the new guidelines require that:

- The participant actively contributes to the development of their service plan. And that family members may help develop the plan
- The support coordinator asks the participant what they want and helps the participant get what they need.
- The individual receives services in the community with the same degree of access as individuals not receiving Medicaid HCBS.
- Opportunities are provided to seek employment and work in competitive integrated settings, engage in community life, and control personal resources.
- The participant's option to choose a private unit in a residential setting is respected.
- The process facilitates choice of services and who provides them.
- The process optimizes autonomy and independence in making life choices.
- The individual is offered choices regarding the services and supports the individual receives and from whom.

Find out more by visiting the CMS website at <http://www.medicaid.gov/>