

MCARE Policy Brief

The National Clearinghouse on
Managed Long-Term Services and Supports
for People with Developmental Disabilities and Their Families

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Participant-Driven Supports: Frequently Asked Questions And Responses

In participant-driven systems service recipients control their own individual supports and play a strong role in shaping developmental disability policy. The approach incorporates ideals, such as community integration and self-determination. At the same time, other systems-level challenges are addressed, including the needs to contain Medicaid spending and accommodate increasing service demand.

At a personal or individual level, service recipients -- participants -- exercise choice over how dollars are used; supports are obtained within some dollar limit; and the participant carries some amount of risk if the budget is improperly used.

At a systems or strategic level, people with developmental disabilities have opportunity to shape policy and practice.

To play a strong leadership role, self-advocates must:

- ✓ Know something about the forces and policies at work,
- ✓ Be expressive about their want for self-determination, community integration and participant-driven supports,

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- ✓ Understand how they can be most effective in the policy arena, and
- ✓ Have opportunities to act, individually and together to make needed systems change. In particular, self-advocates must be a part of the decision-making teams that are responsible for system development.

When compared to historical practices, participant-driven supports imply a fundamental shift in the flow of money and power in the service system. (See MCARE Policy Briefs #2 & 3, entitled *Developmental disability services at the century's end: Facing the challenges ahead* and *Meeting the challenges ahead: Self-determination, fiscal responsibility and participant-driven supports*.)

Moving from the concept of participant-driven supports to the actual practice, however, has not been easy. Questions abound and answers are sometimes difficult to come by. The questions asked touch on a number of areas, such as the capacity of individuals to play empowered roles, mechanical “how to” issues, financing and cost, and impacts on service providers and other system structures. Professionals, self-advocates, and advocates alike have been working to resolve these issues, putting the puzzle pieces of participant-driven supports together. While there are no “final” answers, the intent of this paper is to identify and address some of the questions currently raised about participant-driven supports.

Thirteen Frequently Asked Questions About Participant-Driven Supports

1. What values underlie participant-driven supports?
2. Is there any one way to do it?
3. Are participant-driven supports a form of managed care?
4. How are individual budgets set?
5. How are individual support plans developed?
6. Will the “broker” be independent, a government employee or a parent?
7. What about participants who have trouble communicating their needs and preferences?
8. Will participant-driven supports expand choices for service recipients?
9. What happens if needs exceed the budget?
10. Who or what manages the money that individuals are allotted?
11. Can Medicaid be used to pay for participant-driven supports?
12. How will service providers be affected?
13. Will participant-driven supports save money?

1. What values underlie participant-driven supports?

Three fundamental values form the basis of participant-driven supports: community integration, self-determination, and fiscal responsibility.

- 3 *Community integration:* In participant-driven support the assumption is made that all people, including those with disabilities, are vital and integral members of our society, communities and neighborhoods. Belonging to a community provides a person with many opportunities for relationships and support. Being a part of a community also gives individuals a chance to contribute to their

community, fostering a sense of belonging, identity, and self-esteem.

"In inclusive communities, we move from focusing on services provided exclusively by agencies to support for involvement in typical community activities, based on the needs and choices of the individual. Disability service agencies work in partnership with community services, support networks (friends, family, peers), and the person with a disability. The primary role is to help connect and support the individual in school, home, community, and work."

James Knoll & Michael Peterson (1992)

- ▶ *Self-determination*: There is no single definition of self-determination. The concept is evolving as individuals with disabilities and others gain experience. Overall, the idea is to assure that participants are free to live their life as they want, and that they receive the supports needed to do so. Of course, as with any other citizen, limits on individual preferences are imposed by a variety of factors, such as civil law or one's personal budget.

Much of the effort surrounding self-determination is guided by these four principles (Shumway & Nerney, 1997):

1. Individuals have the freedom to plan their own lives and make life choices.
2. Individuals have authority or control over one's own life, including control over resources so that needed and preferred supports can be acquired.

3. Individuals have access to the support they need and opportunity for increased community integration.

4. Individuals take on the responsibility of living in interdependent communities, participating in and contributing to their community.

- ▶ *Fiscal responsibility*: Unequivocally, related to freedom is responsibility, including fiscal responsibility. With growing wait lists for developmental disability services and pressure to contain Medicaid spending, an emphasis on fiscal conservatism is necessary.

In participant-driven supports, an individual receives the support needed – no more, no less. The strategy is meant to contain spending, while assuring that funds are accounted for and individuals receive the supports they prefer.

Participant-driven supports, through the use of capitated budgets and other managed care technologies, strive to contain costs, but also to deliver quality supports.

2. Is there any one way to set up a participant-driven system?

No, there is no single best way to proceed. The idea is to establish a service and support system where the values of community integration, self-determination and fiscal responsibility are put to practice routinely. There are a variety of ways to achieve this goal, and no set way has won out over others. Individual state strategies are influenced by local values, service

system history, system capacity and financing, politics and other factors. In fact, the diversity in the approaches taken is a strength of the present change process. The variety allows experience to be gathered from multiple perspectives, hopefully with the result of shaping systems to be most effective.

3. Are participant-driven supports a form of managed care?

Participant-driven support systems make use of selected “managed care” tactics, but strictly speaking are not a form of managed care.

The term “managed care” refers to strategies that reduce costs and maximize the value of services by controlling spending and service use. Thought of in these broad terms, participant-driven supports may seem like a type of managed care. However, there is an important distinction revolving around the control of resources.

In managed care systems a “payer” (e.g., a state agency) contracts with a “managing entity” to operate the service system. The entity may be a private or government agency.

Working with a fixed budget, this entity assures that adequate services are delivered to a specified group of people. The entity stands to over-spend or under-spend depending on how well it controls costs and maintains acceptable service quality.

Because it accepts this risk, the entity controls what services are used and by whom, and the price paid. Service providers can make some service related decisions, but such freedom exists within

pre-set parameters and extraordinary requests require approval.

The idea is to curb the use of inappropriate or unnecessary services, or to get individuals to use less expensive alternatives. Additionally, the entity may coordinate competition among providers to assure service availability and drive prices down.

In participant-driven systems there is no need for an overarching third-party controller; The payer may work directly with the service recipient. The individual, granted a budget amount, controls what supports are delivered and by whom, and the price paid. Of course, there may be limits to such control, but the idea is to set the person in charge of his or her own life.

This is not to discount the need for overall systems management. To manage effectively the risks to the individual and the system, managers may insist on using various protocols to minimize associated risks. Additionally, while individuals may prudently act in their own personal interest, the system must also account for the collective well being.

As a result, participant-driven systems may also utilize local or regional administrations to assure the payer that: (a) resources are being effectively allocated, (b) personal budgets are not excessive, (c) unforeseen support needs are addressed, and (d) systems infrastructure is maintained (e.g., quality monitoring, staff training).

Aside from this distinction, however, participant-driven systems can make use of several managed care strategies. Four examples include: capitation, risk

management, service substitution and unified funding.

- ▶ *Capitation* is a method of service financing where the payer pays a fixed amount of money per person to pay for needed services. Capitation changes the basis of payment from a “fee-for-service” arrangement to a fixed, global payment per person. By using capitation, the incentives switch from providing the most units of service to finding the most economical package of supports.

Payers can assign set amounts directly to individuals as “pre-authorized budgets.” Or payers can issue local entities a capitated amount to support some number of people. These entities may pass down pre-authorized budgets to individuals or work out individualized budgets based on a person by person planning process.

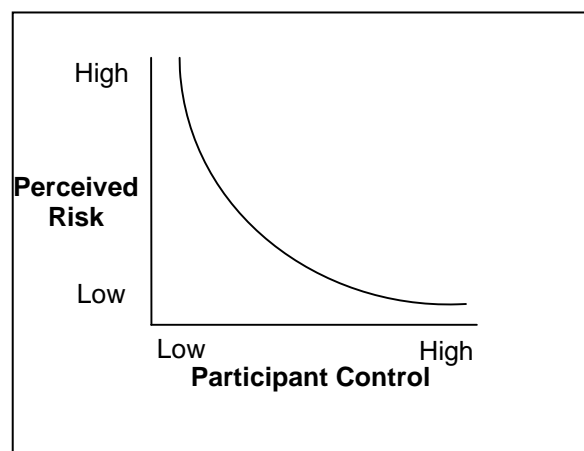
- ▶ *Risk management.* In managed care risk is the financial uncertainty associated with agreeing to provide all needed services to participants in exchange for a fixed payment (the capitation). The risk is held by the entity bearing the burden when costs exceed payments. Where the entity provides services at under-budget costs, it profits. Where it overspends, it takes a loss.

In participant-driven support systems, risk is passed down from the payer to the participant, although an intermediary agency may also be involved. It is presumed that individuals will spend prudently; On average supports will be purchased that offer the best value for the money.

Yet the control exercised by participants is not free. With control, comes risk. Participants are expected to spend within their budget and select effective support-givers, and where things go wrong the state system may not be an able or willing source of additional support.

Systems managers, however, understand that participants cannot carry all of the risk associated with supports delivery, and that risk must be shared. This means that safety precautions must be established to assure that personal crises are resolved and prevented when possible. When sharing risk with participants, system managers also may impose procedural requirements to assure that the risk for all is minimized. This is the price that participants pay for the safeguards. In fact, there is a likely relationship between the amount of risk systems managers perceive and the amount of control they are willing to grant participants.

The risk to individuals can be lowered by budgeting carefully, providing ample support or forming a “risk pool” set-aside to assist individuals whose



support demands exceed their budget. Where safeguards like these are in place, risk is minimized and the control participants have increases.

- ▶ *Service substitution* is the process by which lower cost supports – yet equally effective and needed -- are used rather than higher cost ones. Service substitution can only operate when there are multiple approaches to satisfy a need. By substituting a less costly service that is equally effective as a more costly one, the goal of fiscal conservatism is met. In fact, participants may prefer natural or unpaid supports over traditional services.

In participant-driven supports it is assumed that individuals will consistently seek the best value for their money, prompting the market to respond with competitive pricing and/or enhanced value.

This process can be helped along by the payer. Payers can channel demand to providers whose services are consistent with the themes of participant-driven supports. For instance, payers can: (a) periodically issue “provider report cards” to help participants choose among service options, (b) set individual budgets to favor certain services over others (e.g., supported living over ICFs-MR), or (c) create a state systems culture through training or technical assistance to promote certain support approaches over others.

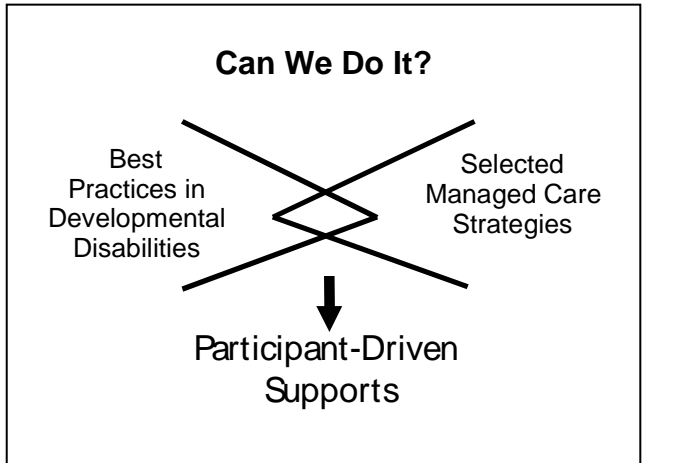
- ▶ *Unified funding.* Currently, developmental disability systems are actually composed of several separate

sub-systems (e.g., institutions, community residential or employment services, family support). Each is typically supported by a mix of local, state or federal resources, though some are funded by a single source only (e.g., state dollars to fund family support). These resources are generally allocated and tied to each sub-system, affording little capacity to move dollars across set categories. Such fragmentation complicates system administration and promotes inefficiency.

Unified funding is an underlying theme of participant-driven supports. The idea is to operate the service system under a single set of policies and to utilize a “global” or combined funding pool. Here, the potential for flexibility in service delivery is enhanced because money can be moved to address individual needs. In addition, the system is simplified and efficiency is more easily achieved.

Current Medicaid policy, however, does not permit absolute unified funding without special federal waivers. Still, states can move toward a more unified system by consolidating existing programs under a single heading and/or covering services under one of the possible federal Medicaid coverages (Smith & Gettings, 1998).

The underlying philosophy behind managed care is to contain costs while assuring that people’s needs are met. While participant-driven support systems are not a form of “traditional” managed care, some managed care strategies are put to work.



4. In participant-driven systems how are individual budgets set?

Setting individual budgets is a tough task with no easy solution. Each state must find its own way, based on some mix of historical costs and new assumptions related to the individual needs and self-determination.

A significant tension revolves around the want to set budgets equitably across all participants while honoring a person-centered planning process. Whatever else, it is essential for the process and the resulting budgets to be judged as “fair.” There is also concern for setting budgets that are ample, yet not excessive, and assuring that when added up individual allocations will collectively fall within the overall budget.

Regardless of the method used, final budget amounts may be discounted for savings to invest elsewhere or to help finance a risk pool that could be drawn upon for emergencies.

Additionally, the matter of when an individual is told of his or her budget amount must be settled. Some argue that individuals should be given a pre-set budget amount to plan around, and so can

plan while knowing what resources are available and modify these plans as needed. While this approach maximizes personal power, it subtracts discretionary power from system administrators. Critics also claim that it is inefficient since people will likely plan to spend their full amount, resulting in few savings.

An alternative strategy is to set budgets after a personal planning process where needs are identified and budgets are subsequently designed to meet the stated needs. Proponents maintain that the tactic is maximally “person centered” and allows systems planners to move dollars where they are needed. One drawback is that individuals are planning “in the blind” and that too much discretionary power may rest with the planning coordinator and the funder.

These issues aside, there are currently two schools of thought for setting budgets. One approach to budget setting is based on quantitative measurement. Individuals are assessed regarding their demographic characteristics (e.g., age, diagnostic criteria), functional capacity (e.g., daily living skills, extraordinary medical, physical or behavioral challenges), available resources, and other variables. Strong attempts may be made to assess what informal or alternative resources the individual can utilize instead of publicly financed services.

Once the assessment is completed, a composite score is tallied and associated with a budget amount. The statistical relationships can grow quite complicated, utilizing hundreds of variables, including historical rates or other systems variables, and correlation analyses. Budget amounts can be set differently for each

person, or individuals can be assigned to groups with an associated budget.

The greatest advantage to this method is that everyone goes through the same formal assessment process, and if the measuring tool is well tested it can be made statistically reliable. Proponents argue that it is a “fair” or equitable way to set budgets. Additionally, from the start system administrators have precise knowledge of the resources allocated to each individual, and so the amount allocated overall.

The second option is to create a budget that is based on a personal planning process that specifies the individual’s needs and preferences. Once a plan is drawn up, a budget is developed based on the cost of needed services and other factors, including use of natural or alternative supports. Budget amounts are calculated based on historical rates or what the service may be purchased for locally. However, once a budget figure is reached, it may require approval by an oversight authority. This added step is necessary so that the sum of the individual budgets does not exceed the total budget for all participants.

An advantage to this budget setting method is that it allows individualized flexibility. The participant’s life is planned and then financed according to the individual’s needs. On the other hand, this method could become tedious -- and costly -- because of the planning time required and the individual’s budget proposal might be rejected several times before it is accepted.

Frustrations may also arise just by virtue of not knowing how high a budget can

reach. Finally, there is concern over how equitable this approach is when played out over time and large numbers of people. Ultimately, individual budgets may depend on how assertive one is during the planning process or on the skills or preferences of the planning coordinator.

5. How are individual support plans developed?

Regardless of how a personal budget is set, the individual must develop a written plan to describe his or her life preferences, support needs, available resources, and a strategy for putting these resources to work to obtain needed supports. The plan may need to be negotiated with a funder and service providers, and may require final approval from a funding authority before it can be acted on.

Putting a plan together generally requires that someone actively collects information, facilitates discussion and prepares the plan. Referred to as a “broker” in several states, this individual acts on behalf of the individual with disabilities.

The broker may well be the most important element in a participant-driven approach, given the responsibility for assuring that support plans are: (a) consistent with the individual’s preferences, (b) within budget, (c) sufficient to meet the person’s needs, and where a group is involved (d) cognizant of the need to assure that sufficient funds are available to meet the needs of other members of the group.

Nerney & Shumway (1996) offer useful guidance on how brokers will perform in a participant-driven system, observing that:

“... individuals who perform these functions arrange with others to carry out the plans developed by the person with a disability or family and arrange for all necessary supports. They do not provide these supports. They become ‘personal agents’ for the person with a disability and that person’s circle or social support network. Of all the roles a broker may assume there are several that seem to fit well with this function:

- ▶ assisting in defining support needs and life dreams;
- ▶ assisting in providing information and resources;
- ▶ assisting in identifying potential formal and informal service providers and supports;
- ▶ assisting in arranging/contracting for services and supports;
- ▶ assisting in ongoing evaluation and other considerations.

One of the primary skills necessary to perform this function is the ability to build on informal supports that may already be present in a person’s life or assist the person to help create these informal supports over time, assisting the person to become connected to their community. Skills in bartering or exchange would be helpful” (p.13).

**6. Will the broker be an independent employee, or work for the government or a provider agency?
Can a parent act as a broker?**

The support broker can be anyone depending on how each state sets up its system. There are, however, at least two important issues to consider: (a) the skills

needed by the broker, and (b) conflicts of interest.

- ▶ *Needed skills:* Any number of people can play the broker role. Regardless of who does, however, a variety of skills are needed to be an effective, efficient support broker.

Simply knowing the service recipient well or wanting badly to be one’s own broker is not enough. Brokers must have the skill to: (a) be a strong advocate for the individual, (b) communicate and listen to the individual, (c) assess important individual life dimensions and preferences, (d) facilitate a personal planning process that may involve several people including the individual, (e) compile a personal support plan and budget according to the specifications of the funder, (f) negotiate and assist in finding, developing or securing supports, and (g) assure that the supports delivered are adequate (Nerney, Crowley & Kappel, 1996).

- ▶ *Conflicts of interest:* There has been much discussion around the topic of who may act as support brokers. Some say that parents should be free to be their child’s broker. Others argue that existing case managers are best positioned to play the broker role. Still others maintain that the broker function ought to be filled by independent contractors. Finally, some service providers argue that their staff can play the role as well as any others.

As noted above, whatever else is considered, the person acting as broker must have the skills to do so.

Yet this person must also have the authority and freedom to honor the preferences expressed by the individual. The broker's allegiance must be to the individual and no other.

From this perspective, some potential brokers may have a conflict of interest. Case managers who are employed by the county or state may find it difficult to follow the lead of the individual. After all, they work for the funder, not the individual. In addition, the culture and routines of the bureaucracy they work for also may tie them down. Individuals may also find it difficult to change brokers and impossible to fire one.

Likewise, provider staff may have a primary allegiance to their employer and a secondary one to the individual. It is hard to imagine that these staff would actively assist the individual to take their business elsewhere.

Parents as brokers raise a special concern. It is argued that parents know their children best, and so can play the broker role effectively. This may work well when the individual is a child, though experience in family support systems suggest that parents often welcome a professional to play this role. A well-trained broker can help parents get the supports they need while freeing parents to focus on parenting.

A struggle, however, takes shape once the child becomes an adult. Parents, assuming that they know their child, may not be listening to the individual as well as they think. Inevitably, parental and individual preferences

may clash. As a safeguard for adults, some argue that parents should be free to parent, while the individual should have access to a broker who listens well and follows through on the individual's stated life preferences.

Because of these potential conflicts of interest, some argue that brokers must be independent, working on their own or within independent "broker agencies." Independent brokers have an allegiance only to the individual and will stay in business as long as this remains so. Critics maintain that adding this player to the system only adds to overall costs. Yet, this option may offer a reasonable solution, but it is not the only one.

Any of the other alternatives can work too, provided that issues related to potential conflicts of interest are resolved. Government employed case managers, for instance, can act as effective brokers, as might brokers used by providers. Brokers like these, however, must be free to honor the support preferences of the individual.

7. How can people who have trouble communicating their needs and preferences take part in a participant-driven system?

Anyone can take part in a participant-driven system. Yet, it is understood that most people with developmental disabilities require support and assistance of some kind. While some require more support than others, or different kinds of assistance, no one is entirely self-sufficient.

To communicate individuals may require special assistance, either by way of adaptive technology (e.g., language board), human effort (e.g., sign language or attentive listening) or both. Gaining this support can be taxing on the individual with disabilities, as well as, the person's support network. In this regard, the importance of having trusted family and friends committed to the idea of self-determination and the individual receiving supports becomes even greater if the participant has trouble communicating.

It should also be pointed out that aside from a narrow focus on communication, many people with developmental disabilities face cognitive challenges that could greatly impede their ability to communicate preferences or manage their own life. Yet, the difficulty some have in making decisions is no justification for limiting the decision-making authority of all participants. Many, many people with developmental disabilities are quite capable of making (or learning to make) key decisions concerning their lives, and systems must be structured to presume or promote such capability from the start.

Consider that:

- ▶ Not all of life's choices are highly complicated. In fact, the smaller choices in life (e.g., choosing what to eat in the morning, when to shower during the day, what to wear, etc.) actually define much of one's personal lifestyle. Most people with developmental disabilities are entirely capable of directing such decisions. To help people to make more complicated life choices, participant-driven systems make a personal advocate or broker available. In addition, wherever possible, the decision making circle could be expanded to include family members, friends or other concerned people as directed by the individual.
- ▶ It is understood that some individuals will not want to or will not be capable of managing complex decisions or required administrative obligations. As a result, participant-driven approaches -- aside from the supports broker -- must make available administrative or fiscal intermediaries a business agent. In addition, participants and their families/guardians, should be able to choose among a variety of options, from little to total decision-making responsibility over their own services and supports.

8. Will participant-driven supports expand choices for service recipients?

Yes, generally speaking, participant-driven support systems increase the choice participants have over the type of supports they receive, how they are delivered and by whom. In fact, "choice of suppliers" is a keystone characteristic of participant-

driven systems. This is because the approach assures that individuals control a pre-authorized budget that can be used flexibly for the supports that he or she needs and values.

In fact, individuals may choose supports that are not offered by traditional developmental disability service providers. Such “alternative supports” can be paid from the person’s budget or acquired at no cost. Paid supports may be offered by an agency or other support-giver who works for a wage. Non-paid supports may be acquired from friends, neighbors, family or various community agencies.

This is not to say that individuals will have “unlimited” or “complete freedom” in their choices. Choice is limited in at least four ways: (a) the fixed budget available to the system, and so to an individual, (b) restrictions on spending related to Medicaid regulations, (c) the availability of preferred services or supports, and (d) state or local guidelines.

- ◆ *The fixed budget available to the system, and so to an individual.* State, county and local money allocated to developmental disability services is generally fixed annually. “New money” may be periodically injected into the system, but administrators must provide adequate support to those enrolled in the system and stay within budget. Inevitably, wait lists result where demand exceeds capacity.

In participant-driven systems the total amount of money available in a system is not altered. Administrators will still need to make do with a fixed budget, a reality that is passed down to service recipients. Individual budgets must

also be fixed, or at least set to a limit. By doing so, administrators can spread fixed resources to large numbers of people, providing each personal control over one’s life while assuring that collective spending stays within budget.

A fixed individual budget means that funds may not be available to support all the choices that a participant makes. Some choices may prove unaffordable. For instance, an individual or his or her parent may want the services of a high-priced residential provider. However, the payer, assuming that the individual’s needs could be effectively met for less money through other options, may set the individual’s budget too low to pay for the service. So, a first choice option may prove unattainable in favor of a less costly alternative.

Likewise, an individual may seek the services of an exemplary supported employment agency. But he or she may also want to live alone in an exclusive part of town. However, the budget assigned the individual may not be ample to support both (or either) of these preferences. The individual, working within the budget, needs to plan and choose carefully over the best use of the available funds. He or she may decide, for example, to live in a more modest residence with a roommate in order to retain the employment agency.

- ◆ *Restrictions on spending related to Medicaid regulations.* There is a great tendency within the self-determination movement to promote people “getting the support they need,” even if it

means buying supports that are not funded by Medicaid. Yet 75% of all developmental disability services are funded by Medicaid, and states have come to rely on the associated federal contribution. Depending on the state, at least 50% of Medicaid funds are composed of federal reimbursements. In using Medicaid, two primary funding vehicles include ICFs-MR and the Home and Community Based (HCB) services waiver.

Medicaid funds, however, are highly regulated. The funds must be used in ways that are consistent with prevailing federal rule and the agreement reached by a particular state and federal authorities. For instance, under Medicaid, cash payments cannot be made directly to the individual. Likewise, not all types of services or supports would be reimbursable under Medicaid.

As a result, if a state seeks to maintain Medicaid funding to support individuals, choices will likely be restricted by the prevailing Medicaid regulations. Of course, much can be done to support individuals flexibly within current Medicaid rules. Smith & Gettings (1998) illustrate in great detail how this can be achieved. States, however, may need to restructure their Medicaid programs to maximize flexibility.

Alternatively, states may also decide to divest somewhat from Medicaid by permitting individuals to use resources to purchase supports that are not Medicaid reimbursable. This strategy may greatly increase personal choice, but lacking the federal Medicaid match,

would reduce the amount of money that individuals have to work with, and so at play in the system.

- ▶ *The availability of preferred services or supports.* Simply put, the service or support that is wanted may not be available. Participant-driven systems will not easily alter this market reality.

An individual, for instance, may seek supported living supports only to find that local providers offer little more than group living services. Having control over a fixed budget will not automatically alter this circumstance. However, such control does create opportunity for the individual to cobble together personal living supports from a variety of alternative community resources. Taking notice, local providers may begin to change or expand the supports offered, an effect that could be magnified if individuals acted together to stir up demand for alternative choices.

Similarly, in rural areas, services and supports may be hard to find, a circumstance that participant-driven systems will not alter. Individuals will likely still need to travel to receive specialized services, or actually move to be closer to needed supports. However, the control over a budget extended by participant-driven systems -- and the competition among providers that it spawns -- may generate growth of local providers or make providers more willing to accommodate difficult to reach communities.

- ▶ *State or local guidelines.* Individual choice may be limited based on local guidelines or inclinations over what is

or is not a proper use of public funds. There may be general agreement between individuals and funders over what supports are needed and over who or what agencies will provide support. Yet instances will arise where individuals seek supports that are not commonly accepted, raising concern over whether public dollars are being properly spent. Ultimately, this issue boils down to whether or not any particular services or supports will be “off the menu.” Funders will need to decide, and their decision will obviously affect the variety of choices available to individuals.

9. What happens if individual needs exceed the budget?

The possibility of overspending in light of unforeseen events is part of the risk incurred by individuals. Participants must plan carefully! Yet when budgets are exceeded, individuals should have a safety net to fall back on.

The trick is to plan ahead for unexpected occurrences. Much can be done from the onset to prevent personal budget crises:

- ▶ Individuals must have an ample budget allocation to start with. Skimping on budgets at the beginning could lead to disastrous outcomes later, if too many end up needing access to emergency funds.
- ▶ The personal planning process must result in a competent supports plan that is within budget.
- ▶ Ongoing monitoring of spending and supports delivery will help assure that individuals stay within budget and head-off some potential problems.

Aside from prevention, however, a risk reserve or “risk pool” must be established to plan for unanticipated events. After all, the best personal budget plans may fall to pieces as an individual’s life unfolds in unpredictable ways. Here, the funder sets aside some amount of money to support individuals when their support needs exceed their budget. Funders typically think about setting this money aside at the front end of the resource distribution process. A percentage of the system’s funds may be set aside from the onset and personal budgets set based on the reduced amount. Or personal budgets can be set first and subsequently discounted. The amount subtracted through the discount is placed into a risk pool.

No matter what method is used, this issue raises a serious concern for funders. A fundamental principle of participant-driven supports is that individuals will act responsibly and prudently. Additionally, individuals accept some of the risk associated with their increased authority. Participants cannot come to expect to plan and spend loosely because a risk pool can always be counted on for back up.

Meanwhile, funders -- most likely a government agency -- cannot easily stand by as an individual falls into deep budget trouble. Ultimately, government bears the risk if things go wrong. As a result, individuals should expect that funders will want to assure that the planned supports are ample, and are delivered properly and at the expected cost.

10. Who or what manages the money that individuals are allotted?

At present, financing matters are handled by the funders (typically government agencies) and service providers. In participant-driven systems this process may stay largely in tact. Individuals will, however, have say over how their personal budget is spent and on what support providers. So, even while the “billing systems” are not altered, individuals will enjoy “choice over providers.

Participant-driven systems may also include two other alternatives.

- ◆ Individuals may choose to manage their own budgets, including payroll and employee tax responsibilities. Where individuals use their resources to make direct payments to service agencies, this may not pose much of a burden. Where individuals are using their resources to pay various workers, however, the associated administrative responsibilities can be substantial. (See MCARE Policy Brief #3; entitled *Meeting the challenges ahead: Self-determination, fiscal responsibility and participant-driven supports*). Note, however, that Medicaid regulations do not permit direct cash payments to individuals. As a result, this option may have only limited utility.
- ◆ A fiscal intermediary or business agent may be made available to assist individuals to manage their budgets, satisfy any associated payroll obligations, and protect individuals from various liability claims (Flanagan, 1996; Agosta & Kimmich, 1997).

11. Can Medicaid waivers be used to pay for participant-driven supports?

There are limits to what can be done, but Medicaid can be used to pay for participant-driven supports. This is essential, given that 75% of the developmental disability system is financed by Medicaid.

The most critical component in the connection between Medicaid and participant-driven supports is the Home and Community Based (HCB) waiver. This waiver provides flexibility to states in the use of Medicaid, and states have used it extensively to finance community service systems. Depending on the state, however, state leaders may find that its HCB waiver(s) must be replaced or amended to accommodate the basic tenets of participant-driven supports. More definitive information on this topic is found in Public Consulting Group (1997) and Smith & Gettings (1998).

In fact, an informative piece by Gary Smith (*Medicaid and participant-driven supports: Straight talk*) on this topic is found on the MCARE website at <http://www.mcare.unh.edu/straight.html>.

12. How will traditional developmental disability service providers be affected?

Participant-driven support requires a shift of systems values, as well as a shift in power. Individuals will have choice in choosing the person or agency to deliver support. This may well expand the provider market since non-traditional or alternative support-givers may be used more frequently. Beyond this potential, the impact on traditional providers will be twofold. There will not only be a change of function for provider agencies, but

provider agencies will also become part of a competitive market.

- ▶ *Changing function among providers.* Agencies must shift away from a program orientation and toward a focus on individualized services and supports. Participant-driven systems require “that agencies move from tidy organizational structures where people with disabilities ‘fit’ into program vacancies to a fluid structure that changes with the desires of the individuals supported” (Smull & Smith, 1994).

This shift results from a significant redistribution of decision-making power. Duckmanton (1997) notes that “There is a kind of food chain in the business of providing services. At the top of the food chain is the service providing managers. At the bottom of the food chain are the people who need support. Participant-driven supports changes this by placing the person needing support higher in the food chain — empowering them.” As a result, provider agencies must not only endeavor to serve individuals but also to “delight their customers” (Magis-Agosta, 1999).

The transition requires that providers rethink their organizational structures and routines. How is future business assured? What type or amount of advertisement is needed? How is “quality” measured and maintained? How are costs assessed and tracked? What type of information is needed to manage the organization effectively and at the least cost?

- ▶ *Becoming part of a competitive market.* Moving to a participant-driven support system will place provider agencies directly in the middle of a competing market.

Ideally, brokers will advocate for individuals and negotiate directly with providers on their behalf. Brokers will articulate how an “individual wants to live and ask how the agency can provide the support and at what cost. Where a satisfactory agreement can be reached, the person with the disability will receive supports from that agency” (Smull & Smith, G., 1994).

Essentially, providers will act as authorized merchants — where participants may “shop.” Because participants can shop for best value, provider agencies may well restructure. Some, unable to compete, will go out of business. Others may find it beneficial to grow bigger by merging or buying out other providers. Under such competitive conditions small or niche providers may be at risk, prompting some to form or join formal networks.

In participant-driven systems the definition of “primary customer” changes for the service provider from the state (or county) to the individual. Ultimately, the resulting market forces are expected to efficiently control the quality and responsiveness of providers. “When a consumer is given a choice of providers, the provider generally attempts to deliver services of sufficient quality to maintain consumer satisfaction” (Dougherty & Eggers, 1996).

13. Will participant-driven supports free up money to spend on other things (e.g. the waitlist)?

One intent of participant-driven supports is to spend available resources efficiently to contain costs and potentially produce savings. The approach presumes that individuals will act responsibly, but also applies selected managed care strategies. The idea is to assure that people determine the course of their lives while wringing out waste and excess supply from the system. People receive the supports they need, no more and no less.

Where successfully applied, participant-driven supports may achieve the desired cost related goals. Actual outcomes, however, will depend on the state. Some states, for instance, may already operate on lean budgets with only modest inefficiencies at play. In these states, there may not be much to gain financially.

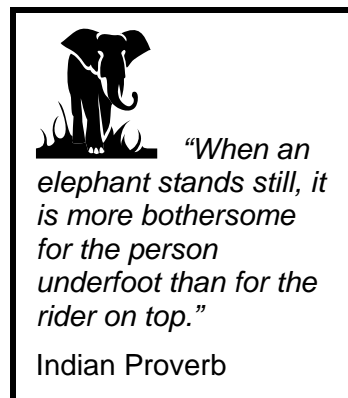
Yet in many states, most would agree that resources are not always put to the best use. There is waste in service delivery and systems administration. For example, too many states suffer from an over-reliance on inappropriate and expensive service options such as public institutions or community ICFs-MR. Others have cumbersome administrative structures or routines that gobble up resources without concurrent benefit. Still others are burdened by provider agencies that have collectively become too numerous, and so inefficient.

If cost related goals are to be met, significant changes in system design and delivery must be made. Simply placing individuals in control of a pre-authorized budget is insufficient. Beyond the benefits

that this practice may achieve on its own, state leaders must be willing to increase system efficiency by making accompanying changes in how systems are administered.

Concluding Remarks

Participant-driven supports offer people with disabilities control over the substance and quality of their own lives, while facilitating a more efficient allocation of resources. While the statement is simple to advance, the required changes in policy and practice are significant.



However, it is a mistake to believe that our service systems have become too complex to accommodate the themes of participant-driven supports. The above questions and responses offer a continuation of the discussion that is unfolding across the country.

As always, change imposes choice. In resolving the issues that participant-driven support systems present, state leaders will no doubt be making a series of crucial choices. Yet the primary problems do not rest within the complexities of “how to make things work,” but in our collective willingness to push forward.

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