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ABSTRACT

This guide discusses participant-driven managed support in which people with disabilities and their families steer their own futures by having more control over the money used to provide long-term supports. After an introductory chapter, chapter 2, "What Is Managed Care," describes managed care, traditional managed care players, and the 10 tools of managed care (eligible population, capitation, risk, care criteria, the flow of money, network management, utilization reviews, care coordination/gatekeeping, service substitution, and quality assurance). Chapter 3, "What Do We Want," discusses the deinstitutionalization of people with disabilities and the move by current services and programs to embrace participant-driven approaches. Chapter 4, "The Way To Go--Participant Driven," highlights participant-driven supports such as: (1) a valid cost containment strategy; (2) allowing consumers to make choices; and (3) giving individuals with developmental disabilities the opportunity to increase control over their lives. The ways in which participant-driven managed supports work at the system level and at the individual level are described. Concerns relating to participant-driven programs are also addressed. The final chapter lists the essential elements of future support systems, including vision, self-determination, flexible services, personal advocates/brokers and business agents, partnerships, unified funding, outcome focus, and cost containment. A glossary of relevant terms is attached. (CR)

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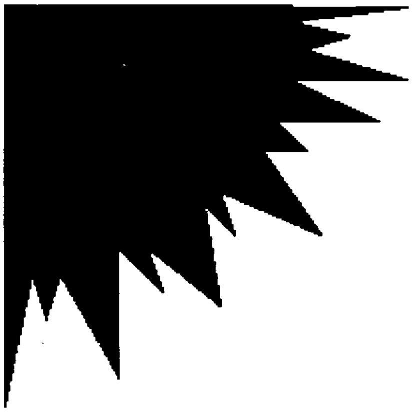

Participant-Driven Managed Supports:

Breaking New Ground

A Handbook on Applying Managed Care Strategies to Developmental Disabilities Services

April 1997

A production of the Human Services Research Institute

Want to learn more? A more comprehensive guide is available from NASDDDS:

Managing Our Own Supports: A Primer on Participant-Driven Managed Supports

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We are very grateful to those who took time out of their busy lives to help us expand our ideas and clarify our thoughts on Participant-Driven Managed Supports. This Handbook is surely better because of their efforts.

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1. Let's Get Started

Are you a self-advocate?

Are you a friend or family member of someone with developmental disabilities?

Do you work in the disabilities field?

If so, this Handbook is for you! This Handbook is about the future of long-term services and supports for people with developmental disabilities. It's about the money available to fund these services, and the power that comes with that money. But most of all, it's about being active in the face of change -- changes in federal and state disability policy that are happening *right now*.

It's about Breaking New Ground!

Right now, two forces are driving major change.

The first involves money. Over the past 15 years, funding for disability services has grown at a rapid pace. In every state, service systems have expanded. **This will not continue**. National leaders are looking for ways to keep down costs -- and spend money more effectively. As a result, more and more states are considering "Managed Care" strategies to promote these changes. Some fear, however, that the coming changes will focus more on cost containment than on the quality of life for people with developmental disabilities.

Second, people with developmental disabilities and their families are pushing, more forcefully than ever before, for services that provide opportunities for them to live in, participate in, and contribute to their community. But more than that, people with disabilities want choices, and a strong hand in determining the course of their own lives.

Participant-Driven Managed Supports offer the tools needed to meet the challenges of change -- to break new ground. Participant-driven managed supports use ***selected*** managed care strategies to offer participants control over the substance and quality of their own lives, while promoting a more efficient use of available money.

This Handbook illustrates how participant-driven systems can work. To make it work, though, people with disabilities, family members, service providers, and others will all need to think and act in new and different ways.

About the Word "Participant"

Participant: One who participates or takes part in something.

To Participate: To take part; join or share with others. (American Heritage Dictionary)

Over the years, many "labels" have been applied to those who use disability services. Are these individuals "clients", "consumers", or "customers"? For a number of reasons, when we talk about *Participant-Driven Managed Supports*, we choose not to use any of these terms to reflect the role that people with developmental disabilities will play in future service systems.

Instead, we choose the word "participant" because it symbolizes an active role -- a partnership. It's a role that pushes beyond traditional client-professional relationships, and expects that people with disabilities will help shape the structure of the system, and make decisions about the lives they want to lead.

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Get Involved!

The developmental disabilities system is going through a MAJOR change. It's BIG! It's really BIG! In fact, it's probably the biggest change since the early 1970's when people started moving out of state institutions, and community service systems were first developed.

And YOU need to understand what's happening, to be part of the group (if not a **leader** of the group) that decides how these changes take place.

Changes are happening at ALL levels of government -- federal, state, and local. Don't be afraid to get involved. Your input is **the most important** -- because this system, after all, affects **your** life.

The main questions that are being asked -- the ones really pushing these systems-level changes -- include:

=> How do we keep down costs?

=> How do we improve the quality of services?

=> How do we serve more people?

These are questions that we all care about, and many people feel that "managed care" holds the answers.

The truth is -- it might - or it might not.

What managed care definitely does do, though, is offer the developmental disabilities field several new **strategies** for addressing these questions and making needed changes.

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Get the Facts!

What is all this commotion around managed care? Why is everyone talking about it? Are states serious about using it to change their disability systems?

What is happening? Many states are thinking about using managed care strategies to change their disability systems.

Why is this happening? At the state and federal levels, there's a lot of pressure to contain Medicaid costs. Developmental disability systems depend heavily on Medicaid funding, so there's a fear that funding won't be able to keep up with the growing service demand.

And the demand for services is definitely growing. People with disabilities are living longer and will continue to need services. Others with disabilities, new to the system, are coming forward to request services (e.g., high school graduates, individuals with aging parents no longer able to provide care at home). Overall, the combined pressures of cost containment and increased service demand are making state leaders look for better ways to manage their money.

When and where is it happening?Managed care strategies are already being used in health care, mental health and substance abuse programs -- and are being considered in developmental disability systems. **Most states are just getting started** -- trying to figure out who should be involved in the planning, and what should be done. Other states are further along, developing plans or trying it out in local communities.

What is Medicaid?

Medicaid was created in 1965 to help states pay the medical bills of low income citizens. Today, Medicaid has three program areas:

1. a health insurance program for low-income individuals,

2. a long-term care program for seniors and people with disabilities,

3. a specialized service program for people with developmental disabilities or mental illness.

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Get Smart!

This Handbook is written for you. Especially if you're someone who wants to sit at the table, understand managed care, and have a say in how it's used to redesign services for people with developmental disabilities and their families.

When most people think of managed care, they think about managed health care -- an HMO. But t**his book is about Managed Long-Term Supports** -- managing services and supports for people with long-term support needs, across a life time. It's **not** about managed health care.

Information & Leadership

This Handbook provides you with a basic understanding of managed care principles and how they can be used to change, even improve, service systems for people with developmental disabilities.

Vision & Direction

The developmental disabilities field now focuses on community integration, meaningful lives, and self-determination for people with disabilities. This Handbook tells you how we got here, and talks about where we're headed.

Money & Control

This Handbook introduces **Participant-Driven Managed Supports**, where people with disabilities and their families steer their own futures -- by having more control over the money used to provide support.

What are long-term supports?

Long-term supports are supervision or assistance given to a person with disabilities to help the individual complete daily living activities (e.g., eating, dressing, communicating, keeping a job), learn new skills, maintain a general sense of safety and well-being, and otherwise pursue a regular life.

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Get Driven! Participant-Driven!

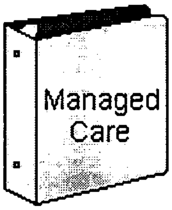
Given the changes in both the developmental disabilities field and the economy, it's crucial that people with disabilities, their families, and others prepare themselves -- educate themselves -- for the road ahead. This means...

Understanding the basic tools of managed care. This can be found in

Chapter 2: What is Managed Care?

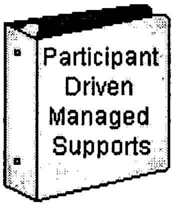
Revisiting our values and vision for a system that is more focused on individuals -- one that promotes community integration and self-determination. This is discussed in

Chapter 3: What do We Want?



Putting the tools of managed care to work in ways consistent with our vision -- designing our own approach to change the system. These are presented in

Chapter 4: The Way to Go - Participant-Driven!!



Getting clear about the key characteristics of future service systems. These eight essential elements are described in

Chapter 5: Breaking New Ground

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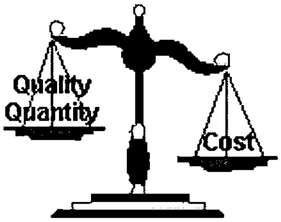
2. What is Managed Care?



Managed Care is negotiated quality -- for a negotiated price -- for a negotiated number of people.

Many states are looking at managed care because they're faced with
(1) a growing number of people, who are
(2) demanding higher quality services, yet
(3) they only have a limited amount of money.

Think of managed care as a toolbox that contains a group of different ways (or tools) to deal with all of these issues at the same time.

There are three main reasons that state systems turn to managed care strategies, and almost always, the reasons fall in this order.

They may be faced with growing service costs, and turn to managed care to hold them down.

They may want to stretch their dollars to serve more people, and look to managed care to help them address their waiting lists.

They may be responding to complaints about the poor quality of services offered, and look to managed care to help define and improve quality.

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The Players

Traditional Managed Care Players

Payer

Managed Care Intermediaries

Service Providers

Service Recipients

The four main players in "traditional" managed care are the payer, managed care intermediaries, service providers, and service recipients.

The payer, or funder, is the one with the money -- the one who pays for developmental disability services. Typically, this is the state or county developmental disabilities agency, or the state Medicaid agency. The payer (receiving federal Medicaid dollars) decides how funds are distributed. On average, Medicaid pays for about 72% of all developmental disability services, and the need to cut Medicaid costs is what's pushing states toward managed care.

From the payer's perspective, managed care is a greatly anticipated opportunity to get control over **how** money is spent, and **how much** money is spent.

The Managed Care Intermediary typically receives a fixed ("capitated") payment from the payer. The most common types of intermediaries are: a Managed Care Organization (MCO), a Managed Service Organization (MSO), or an Administrative Service Organization (ASO). The differences between these are related to their different responsibilities.

The MCO is responsible for seeing that services are provided, as needed, to recipients without exceeding the money paid. In fact, the MCO's goal is to "save" or "make" money -- by spending less. These savings become their profits -- unless their contract with the payer states otherwise. The MCO works with a network of providers, and does not directly provide any services or supports.

The MSO is like the MCO with one major exception -- it may provide services and supports itself.

The ASO doesn't shoulder the financial risk that the MCO and MSO do. It is paid a flat fee to provide administrative services only, supporting organizations who handle other intermediary responsibilities.

From the intermediary's perspective, managed care presents an opportunity to balance the cost, quality and quantity of services.

The service providers are organizations or individuals who provide various services and supports. These include formal organizations (non-profit or for-profit), informal affiliations (for example, church groups, community cooperatives), and other individuals (paid and unpaid) -- basically, any group or person who provides supports to service recipients.

From a provider's perspective, managed care can mean a lot of uncertainty and anxiety. Many providers have had long-standing relationships with payers, and now they will have do deal with a new player (the intermediary) stepping in -- likely changing how they negotiate to offer services.

The service recipients are those who receive services through the managed care system. For the most part, this means people with developmental disabilities, but it could also involve "secondary recipients," such as family members.

From the perspective of service recipients, managed care is scary because it's highly technical and not well understood. Many also fear that managed care might result in their losing some of their supports.

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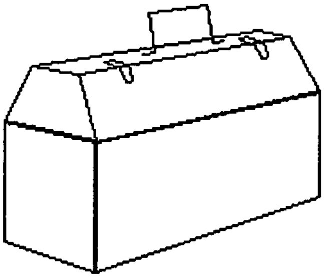
The Ten Tools of Managed Care



Tools of Managed Care

1. Eligible Population

2. Capitation

3. Risk

4. Care Criteria

5. The Flow of Money

6. Network Management

7. Utilization Review

8. Care Coordination/ Gatekeeping

9. Service Substitution

10. Quality Assurance

These are the major tools of traditional managed care -- the words you'll hear when people talk about it. Some of these tools are *not* new to the disabilities field. They are being used around the country. What *is* new, though, is that managed care approaches allow us to put these tools together -- to keep down costs while maintaining quality or serving more people.

Below, we describe the ten tools separately. But, it's important to remember they are all very connected, and are not as distinct as this suggests.

Eligible population -- the group of people to be served by the Managed Care plan.

A state agency may put **all** or **some** of its current recipients into a managed care plan. Or, the plan could bring in even more people (e.g., those on a waiting list). The key question that must be addressed here is: how will "eligibility" be defined? In other words, who will get in -- AND who will be left out?

Capitation -- the payment offered to cover service costs for the eligible population.

The payer sets a capitation amount for the group served in the managed care plan. This is how the payer controls costs. It will pay up to the capitation rate, but not more.

The capitation rate can be determined by using a *straight* average -- where everyone in the group gets the same amount of money for services. Or, an *adjusted* average can be used -- where the rate varies according to different levels of need.

Risk -- the uncertainty that exists when agreeing to provide all needed services for a set amount of money.

There are two sides to risk: 1) the potential to overspend the capitation (added costs); and 2) the potential to underspend the capitation (savings or profit). Risk can be held by any of the players, and each can carry full, partial, or no risk.

One possible way of sharing the risk is to make the intermediary responsible for covering costs within a certain percentage above or below the capitated rate. This is a "risk corridor" (see below). Another approach would require the player with the risk (e.g., intermediary, providers) to set aside "reserve funds" to cover any unpredictable or extraordinary costs. Or, in yet another option, the payer could cover the most costly services outside the capitated rate (see "carve-out" below).

What's A Risk Corridor?

One Example

A payer contracts with an intermediary to manage a budget of $500,000 - and assure that 50 people get the supports they need. They agree to a 10% **risk corridor**.

10% of $500,000 is $50,000.

If the intermediary spends between $450,000 and $550,000 (the corridor) to serve the 50 people-- it must cover ALL of the costs. Within this range, the intermediary gets to keep any savings - or has to pay for any cost overruns.

If the intermediary spends less than $450,000 -- it gives back to the state any added savings. If it spends more than $550,000, the state pays for costs above that amount.

Care criteria -- the standards used to determine what services are available to a person, based on that individual's needs.

Care criteria could be a list of allowable services, a "benefits package", or could simply require that services meet certain conditions, such as being part of an approved personal support plan (PSP).

Certain specialized services may be excluded from the standard package -- called a "carve-out". These services are then available through separate contracts outside of the basic managed care plan. Carved-out services may have special capitations or be purchased on a fee-for-service basis. Often, services are carved out when they are especially expensive, or when demand for the service is unpredictable.

The flow of money -- how money is distributed from the payer to others.

Typically, funding flows from the payer to an intermediary, from there to service providers, who then deliver services (or in some cases, cash payments) to individuals.

The one with the money is the one with the power in a managed care system. Where you sit in this chain of command dictates how much power and control you will have. By changing the flow of money, the balance of power shifts.

Network management -- the formal arrangements for coordinating a group of providers in a managed care plan.

Network management is usually handled by the managed care intermediary. The network is made up of service providers. Management includes recruiting, contracting, and monitoring the performance of these service providers. In addition, the intermediary is ultimately accountable to the payer for all network performance.

To increase their appeal to intermediaries, providers may organize as "integrated service networks". Being part of a network allows a provider to share administrative costs with other agencies in the network. The larger the provider network, the more potential for a service recipient to have choices among providers.

Care coordination/gatekeeping -- when someone (or agency) is responsible for developing or planning the mix of services that an individual receives.

In typical managed care plans, this function is different for people with extraordinary needs or high service use than it is for the majority of participants. People with modest or predictable service needs likely receive only basic coordination. People with more intense and less predictable needs may have a designated *care coordinator* or *case manager*.

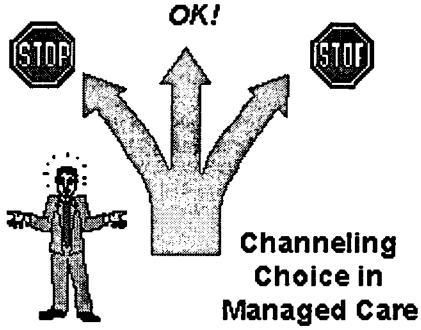
The care coordinator/case manager has a gatekeeping role, seeking to keep service costs within reasonable bounds. The concern here is who this person works for -- an intermediary, a service provider, or service recipients. This will guide who the coordinator is ultimately responsible to, and will affect whether anyone is truly advocating for service recipients.

Utilization review -- a process that assures that services being provided are necessary, effective, and offered at the lowest reasonable cost.

This can be fairly complex -- using specialized staff or a review board. Some parts can be handled by the managed care intermediary and others by the payer. Reviewing how services are used, whether or not they're effective, and how much they cost can be done before, during, or after services are provided.

Successful utilization review depends on accurately determining whether a service is needed and whether it has been effective.

Service substitution -- requiring the use of lower cost (but equally effective) services in place of more expensive ones.



Service substitution works when there are several options to address a certain need. Managed care requires that if one service is as effective as another one that costs more -- the first one must be used. Of course, *who* defines effectiveness is critical.

Service substitution has the potential to expand *and* limit choice. It may encourage "channeling" -- where service recipients must use particular providers -- because they cost less. BUT, because it focuses on using low-cost services, it can also encourage competition among providers and development of new, more efficient services.

Quality assurance -- process to assure at least minimal performance, protect service recipients, and improve future services.

Traditional quality assurance emphasizes quality control, assuring basic health and safety and service delivery. Under managed care, ongoing quality improvement comes to the fore, using internal processes to assure increasing effectiveness of services. Quality assurance requirements are a major component of managed care plans.

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3. What Do We Want?

| Integration | Participation | Contribution | Opportunity |
| Normal Rhythms of Life | Self-Determination |

People with developmental disabilities want to exercise self-determination, participate in all aspects of society, and be valued and respected citizens in their communities.

More and more, it's recognized that ALL people -- regardless of ability -- should have opportunities to *fully participate in every aspect of community life*.

People with developmental disabilities expect, like others without disabilities, to live in the community and have their life follow a normal rhythm -- one that involves home, work, and play. They expect to be physically and socially integrated into the community -- and to participate and contribute to their community -- like everybody else. Also, the extent to which each person has control over life's many choices and decisions becomes a measure of their independence and well-being.

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The Past

It wasn't always this way. Before 1970, there were few service options for people with developmental disabilities. They could either stay at home with their families (receiving little or no services), or they could leave home to live in a large state institution. As a result, the institutional population reached its peak in 1967, at about 194,000 people.

In the early 1970's, two things happened to change the disabilities field. First, there was an overall change in how people thought -- they began favoring the presence of people with disabilities in society. And second, across the country, there were discoveries of appalling conditions in the institutions.

About that Word "Institution"

The word "institution" generally refers to a large residential facility that houses more than 16 people. The facility typically offers a full range of services (e.g., food, medical, laundry, instruction, therapies) so that there is little need for the residents to leave the grounds. Further it often imposes life routines (e.g., regular menus, regulated activity periods) that reduce the resident's opportunity to make everyday choices. In essence, the institution offers a segregated and self-contained lifestyle.

Since that time, the field has experienced many changes. Over the past 25 years:

The number of people living in institutions has steadily decreased.

The cost of institutional care has risen greatly.

Repeatedly, studies show that people are better off living in the community than in institutions.

Individuals who moved out of institutions -- and many others who stayed in their hometowns -- typically got services from the emerging private sector. They lived in group homes, used special buses or vans to get around town, and attended segregated schools and day programs. Resources already available in the community for everyone's use were largely ignored. As a result, individuals with disabilities lived in communities, but did not necessarily participate in their communities.

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The Present

Today, it's not enough simply to live in the community. It's now widely accepted that people with disabilities want to, and should, live their lives like anyone else (to the extent possible). There's a growing commitment to assure that people have opportunities to participate in and contribute to all aspects of community life. NOW, individuals with developmental disabilities expect to have opportunities to attend regular schools, participate in regular classrooms, live in ordinary homes, have real jobs, and ride ordinary buses.

Also, in growing numbers, people with developmental disabilities are playing greater roles in planning their own futures. Although, the field is still struggling, it is making progress in moving from a professionally-directed system to a "participant"-driven system. For these newer person-centered approaches to work, it's essential that policy-makers and program administrators respect the preferences of the people they serve -- and give people opportunities to control their own lives.

This is not new! We've already shown that participant-driven approaches do work! People with disabilities -- even severe disabilities -- can express real preferences and take real control of their supports.

In recent years, many types of services and programs have begun to embrace participant-driven approaches (e.g., supported living, supported employment). Participant-driven approaches are most evident, though, in family support and personal assistance programs.

Family Support

Family support programs offer a wide variety of services and supports -- and families have great control and flexibility in the supports they choose. This is especially so in the states where cash payments or vouchers are offered. Here, families can purchase "whatever it takes" to help them meet their caregiving needs.

Many family support programs place choice, control and flexibility at the heart their program. Families are encouraged to develop their own family support plans, and participate on advisory or governing committees for their local and state programs.

Personal Assistance Services

Personal Assistance Services include support with personal care, mobility, and household affairs, but also can involve help with employment, transportation, community participation, communication, and even parenting -- all to enable greater independence.

In "consumer-directed" personal assistance services, participants have choice and control in : 1) hiring and firing their personal assistant, 2) determining the supports they'll receive, and 3) training, supervising, and paying their assistant. They also have opportunities to participate on committees to plan state and local personal assistance programs.

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4. The Way to Go -- Participant-Driven!

We want a system that emphasizes the values of self-determination and full community participation for people with developmental disabilities. But, we have to hold down costs. We must put these goals together, and managed care offers us strategies for doing so.

We believe "Participant-Driven Managed Supports" are the way to go.

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What are Participant-Driven Managed Supports?

A participant-driven managed support system is where participants and/or their advocates are involved at all levels and in all phases of decision-making.

Participants have significant say in how the system is designed, how it operates, and how it's evaluated -- AND -- they have great control over how funds are used to meet their needs.

All Levels -- All Phases
Participant Involvement

Participant-driven managed supports are the "Way to Go" -- because they're:

1. A Valid Cost Containment Strategy -- Participant-driven managed supports keep a lid on costs because decisions about what is "important" or "needed" are driven by the individual -- and only what the participant receives is paid for.

In fact, experiences with family support programs show that when families are given cash payments, they typically spend their money wisely and carefully -- sometimes even spending less -- because families purchase only exactly what they need.

2. Consistent With The Field -- Participant-driven managed supports offer people with developmental disabilities opportunities to:

=> Make choices -- and have the power and resources to control their own lives.

=> Decide what they need, how it's delivered, and by whom.

=> Get support to participate in and contribute to their community's economic and social life.

3. Sound Practice -- Participant-driven managed supports give individuals with developmental disabilities opportunities to increase control over their lives. Alone, or with assistance, people with developmental disabilities are encouraged to recognize their own preferences, gain needed life skills, and make decisions affecting their lives.

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How Would Participant-Driven Managed Supports Work?

In participant-driven managed support systems, participants have meaningful roles at both:

The systems level -- Policies and practices are greatly influenced by what participants and their families say they need and prefer; and

The individual level -- Participants and family members (with support as needed) control and direct the supports they personally receive. Essentially, this model changes the flow of money.

At the Systems Level

At this level, people with disabilities (or family members) are partners in shaping policies and services.

In shaping policy, participants are part of the team that designs the new system.

Participants are partners in planning the managed supports system, and are represented on all relevant boards & committees.

Participants are included in decisions that establish policies for the managed supports system (e.g., eligible population, capitation).

Participants help determine how to evaluate the managed supports system.

Participant involvement is woven into all contracts with intermediaries and providers.

To make sure this partnership works, resources must be set aside to cover participants' costs for participation -- and for training or support.

In shaping practice, participants have a formal role in guiding how policies translate into practice.

In a participant-driven managed supports system, participants have ready access to information so they can make "informed choices". They are assured a leading role in decision-making, service options are flexible enough to accommodate a wide variety of needs, and there is a prompt, easy to use, and fair appeals process.

At the Individual Level

At a personal or individual level, a "participant-driven" approach means that people/families, rather than third parties, choose how their dollars are used, within certain parameters. For example, the payer will limit the individual budget, or may restrict the types of services that may be provided.
Participant-driven approaches can take many forms. However, all will have these five characteristics:

1. **Participants have control over pre-authorized dollars that can be used flexibly to meet their needs**. The amount can be assigned to each person separately, or to a group of people (as in a block grant) where the total amount is used to meet the needs of all group members. The money can be distributed in cash, as vouchers, as credit, or some combination. The risk of not being able to cover a specific person's needs is lessened when the total dollars can be used as needed for all members of the group.

2. A **Business Agent** is required to help people manage their money and meet any new administrative or legal obligations. Here is where the pre-authorized dollars sit. The business agent is an ASO, not an MCO or MSO (which has control over the money). Because people with disabilities have control over their resources, they may take on a variety of new responsibilities:

Directly paying support givers or providers,

Filing and withholding taxes for support givers, who the Internal Revenue Service considers employees of the participant, and

Completing various forms required by the IRS, Department of Labor, and other agencies.

Business agents perform some or all of these tasks. They provide bookkeeping and other business-related services. They deal with payroll, make sure bills or taxes are paid, and that benefits (e.g., worker's compensation) are available to support givers. Business agents offer support to participants without taking away their control.

3. **A Personal Advocate/Broker** helps participants to develop their support plans and get the supports they need. The advocate/broker looks for ways to meet participants' needs by using informal supports and more formal (or traditional) services. An advocate/broker provides information and assists in connecting people with their communities. This person can also represent participants when dealing with providers (in getting and monitoring supports). Whoever the advocate/broker is, he or she will likely be required to have the skills necessary to complete these tasks.

When specific dollar amounts are allocated to individuals, the advocate/broker helps to assure that the amount is spent in the most efficient way. When the money is allocated as a "block grant" to meet the needs of a group of members, the advocate/ broker works with participants to develop personal budgets, but must also assure that the needs of all members are met within the block grant budget.

In either case, the advocate/broker is responsible for making sure the plan honors the person's preferences, provides incentives for containing costs and keeping within personal budgets, and meets participants' needs. **The advocate/broker's first loyalty is to the participant** -- assuring that the participant has real choices to make, and that he/she understands what each choice means.

When the advocate/broker works for several participants, he/she can help participants to create networks with greater purchasing power for better rates. The advocate/broker can also organize exchange networks or cooperatives for sharing resources. Overall, the personal advocate/ broker is responsible to the whole group for getting the most supports, for the available money.

4. Individuals have a **choice of service suppliers**. Providers and others act as authorized merchants -- where participants may shop. Participants have an incentive to use natural or informal supports (e.g., friends, neighbors). This way, money "saved" can be used for other purposes -- for themselves or for somebody else. For quality assurance purposes, there may be some basic requirements (e.g., training) that providers have to meet.

5. **A switch in thinking from a wholesale to a retail market**. In traditional managed care, negotiations happen between the payer and the intermediary (e.g., between the state and the MCO). This is similar to a wholesale market, where negotiations are primarily between supplier and merchants.

In participant-driven managed supports, participants have control over resources and shop for the best supports at the lowest price. Here, individuals control the resources, so providers compete to get their business. Providers may opt to network (as in traditional managed care) to make themselves more attractive to participants.

Think of ...

1. The allotment of dollars tied to participants as a debit card with a charge limit that can be used flexibly

2. Business agents are like a debit card processor

3. Personal advocates/ brokers to help develop support plans and access supports

4. Providers and others as authorized merchants

5. A switch in thinking from a wholesale market to a retail market

Gary Smith, 1996

"Service recipients, working on limited budgets, will spend more prudently to get the most value for their money, and customer-driven arrangements will spawn a market economy in which those providers representing the most value will survive."

Gary Smith, 1996

What this all boils down to is that participant-driven managed supports use many of the same tools as traditional managed care, but use them in somewhat different ways. Together, these differences add up to a very distinct approach. Perhaps the most important differences in participant-driven approaches are:

Flow of money: The biggest difference, money flows from the payer to participants (individually or in groups), who then purchase services from providers.

Risk: Participants as well as intermediaries and payers carry some of the financial risk. For participants, the potential risk is not being able to afford certain services they feel they need or want.

Care coordination: Personal advocates/brokers work for participants rather than intermediaries or payers.

Utilization review and service substitution: These formal processes, controlling what services are provided, are not necessary because the participant and personal advocate/broker together decide how to spend limited funds.

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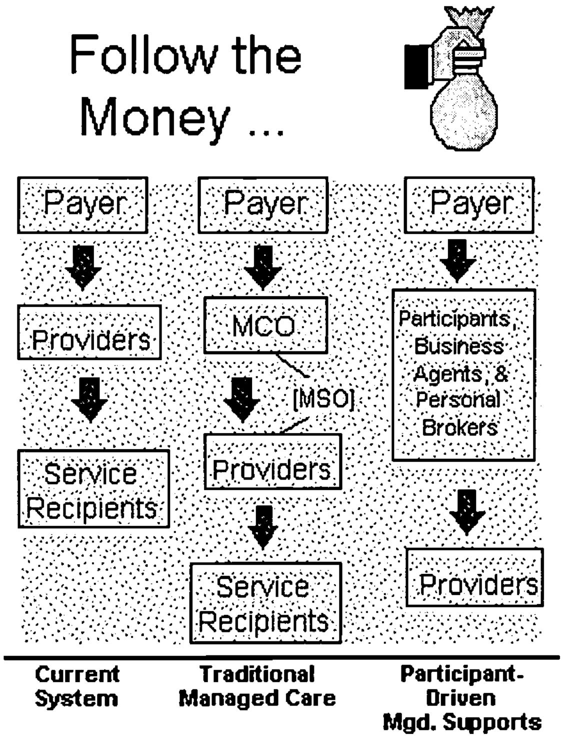
What are the Concerns?

Participant-driven managed supports pose some important concerns that must be looked at -- even though many are technical in nature and, given time and experience, can be resolved.

These concerns include: a) opposition to putting control in the hands of participants, b) participants' decision-making ability, c) whether distributing resources directly to participants can really work, d) the ability of participants to bear financial risk, and e) defining acceptable choices.

Some might oppose a participant driven system. Participant-driven managed supports alter how the current systems operate, affecting how the money flows and who has control and influence over disability policies and services.



This graphic shows three different ways that money can flow. Column 1 shows how money typically flows in our current systems -- from the payer to providers, who then offer services and supports to individuals.

Column 2 shows how money flows in a typical "managed care" system -- from the payer to an intermediary, next to providers, who then offer services and supports to individuals.

Column 3 shows how the money would flow in a Participant-Driven managed supports system -- from the payer to participants (with business agents to handle administrative duties, and personal brokers to assist with planning), who then purchase supports from the provider they choose.

Changing how money flows changes who has the power and control. As participants get more control over service dollars, they become bigger players in deciding their futures, and the future of the service system. Of course, as participants gain control, others will lose some of the power they once held.

People with severe disabilities may not be able to make complex decisions in a participant-driven system. Critics argue that participant-driven systems aren't realistic for some people with severe cognitive disabilities. But, just because some might have difficulty or need significant support in making decisions is no reason that ALL should lose the opportunity.

A better solution is to offer a range of options to participants -- so they can choose to do as much or as little decision-making as they'd like within established parameters. Personal advocates/ brokers are vital to supporting participants in this decision-making. In addition, business agents could pick up some of the responsibilities that participants do not want.

Giving money directly to participants will be difficult to do. Several examples exist where money goes directly to participants. The Supplemental Security Income (SSI) program, for instance, provides cash payments -- and in developmental disabilities, over 20 states offer cash payments to families who care for their children with disabilities at home.

An alternative to cash grants is a voucher system, where individuals have a strong say over how the money can be used. Participants would get voucher coupons that can be "cashed in" for services with participating providers. Many states are experimenting with vouchers. The defining feature of all these examples is that the participant has a lot of control over how money is spent.

Cash Subsidies and Vouchers

Voucher: a payment method pre-authorizing a specific type and amount of services that a person can buy.

Cash subsidy: a payment method providing a direct cash amount for purchasing goods, services, and/or supports. However, there will be difficulty in distributing money to adults with developmental disabilities due to regulations in the Medicaid program. Current regulation dont allow direct payments to Medicaid recipients.

People with disabilities and families will have to carry some risk. Having control over money means assuming some amount of risk. In participant-driven systems, people with disabilities and their families must realize that: a) their budgets are limited and they need to stay within the limits, and b) they may have certain legal liabilities. Specifically, they might have to deal with:

- Not having enough money when unexpected events happen, such as a medical crisis. Here, participants (or groups of participants) might want to protect themselves by creating a reserve fund for emergencies.

- Having their payment viewed as income, and having to pay taxes. In family support, however, there is legal precedent that when a family gets funds toward a greater social benefit, it is not seen as income for tax purposes.

- Being viewed as an employer -- who is responsible for paperwork, liability, and other administrative tasks.

The business agent can help here by handling paperwork, tax, and other requirements to protect the participant from various liabilities -- and can assist participants in setting up a reserve fund for emergency situations.

A fixed budget might not give participants enough money for certain services. For example, a participant who wants ICF-MR services may not be able to afford them because it's very expensive and the participant's needs could be met for less money through other options. Likewise, an aging parent may want their adult child to leave home to live in a community setting with paid supports. However, the individual's budget may be set too low to pay for out-of-home services. The role of the personal advocate/broker is important in trying to find the best match between participant needs and available resources.

A critical issue is how the individual budgets are set, and how well the personal advocate/broker is able to negotiate for the best package of supports. People's needs, preferences, abilities, and the quality of services must be kept in mind. Limits cannot be set arbitrarily simply to contain costs.

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We Are Learning To Do This

Participant-driven managed supports are, so far, untested on any large scale. There are technical and political issues that cannot be ignored if we want to proceed. They must be honestly faced and dealt with. Already, people from state to state are tackling these concerns, and trying to develop participant-driven systems that work.

Over the past year, several states have pushed hard to develop a participant driven system. Colorado, Georgia, New Hampshire, Ohio, Pennsylvania, Rhode Island, Vermont, and Wisconsin are just a few of the states that have begun to plan seriously for reforming their service systems -- to make them more participant driven. The process has not always been easy, but there's a strong commitment to keep on talking -- to figure out how to make it work.

Helping things along, the Robert Wood Johnson (RWJ) Foundation has funded a few projects exploring new ways to finance and deliver supports. In 1993, RWJ funded a pilot project in New Hampshire testing a participant-driven service delivery approach. Evaluation results found that this project, involving about 50 participants, resulted in improved quality of life for participants, as well as cost reductions. Based on that experience, in 1996 the Foundation made $5 million in grants available (over three years) to states wanting to change their state policies and practice. The selected states will explore and test various participant-driven approaches to service delivery.

Common to the approaches being explored is the expectation that participants (acting alone or with chosen others) will decide how limited service funds are spent. The approach builds on the premise that participants know their needs, will spend carefully, and that eventually the service system will supply what people want, using competition among providers to hold down costs and improve quality.

The approach places individuals in the lead. But beyond personal self-determination -- a system can be designed where participants act together to provide mutual support and to influence the service system.

Participant-driven systems, at their core, challenge the field:

Do we have the will to make changes in how the money flows?

Can we move from the current system to one that puts people at the center?

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5. Breaking New Ground

Participant-Driven Managed Supports
Break New Ground...

Participant-Driven Managed Supports give people with developmental disabilities real control over their services, supports, and lives.

Participant-Driven Managed Supports take *only the best* strategies of traditional managed care, and adapt them to better address the long-term support needs of people with developmental disabilities.

People resist change. It's tough to let go of the past, and the future is uncertain.

We now face a future where purse strings will be pulled even tighter, while people with developmental disabilities continue to demand even more say in directing their own lives.

But, managed care is coming -- and participant-influenced decision-making should guide its arrival. This is why we, collectively, need to decide what kind of future we want -- and how we're going to create it.

Participant-driven approaches are being tested across the country -- in programs big and small. Managed care strategies are filtering into disability systems -- in some states slowly, and others more rapidly.

No matter the specific circumstances that your state or local community faces, we believe that these eight elements are ones that should be featured in any future developmental disabilities system.

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Essential Elements of Future Support Systems

Where imagery leads, policy follows, and behavior results.

Ellen Goodman

Vision: A new support system must be built upon a common vision -- which is tied to participants' quality of life. It must emphasize opportunities for people with developmental disabilities to be included, to participate, and to contribute to their local communities, and determine the substance of their own lives.

Self Determination: Participants must control the funds for their own supports. They should have their own budgets to buy basic supports for living, work, and community inclusion; be able to choose the services they want; and choose who provides those services. They must also be involved at the systems or policy level -- part of the planning and policy-setting team.

Flexible Services: Programs should be "unbundled", so that different mixes of services and supports -- and a variety of providers -- can be accessed by participants. Providers or provider networks compete to be chosen by each participant to provide needed supports.

Personal Advocates/Brokers & Business Agents: Personal advocates/ brokers should be available to help participants develop their person-centered plan and budget. This advocate/broker looks for ways to meet the person's needs using traditional services *and* informal supports. They provide information, make community connections, and can represent the participant when dealing with providers. Participants must also use a business agent who serves as the administrative intermediary (ASO). They help the participant with required paperwork and legal responsibilities.

Community Partnerships: Participants must be equal partners in all planning efforts -- and collaboration must be nurtured among all potential sources of support in the community. It's important to build upon existing networks (family networks and community networks) -- tapping natural supports, community groups, generic service providers, and using or creating bartering networks.

Unified Funding: Funds should flow simply to the local level and to the participant. Currently, many programs have categorical funding -- where money must be used for specific services only, and must follow specific rules. By continuing to operate this way, we would continue to have a fragmented and inefficient system. A single funding base would eliminate many of the regulations associated with categorical funding, would allow greater flexibility for participants, and require less paperwork for administrators.

Outcome Focus: The quality of a service system should be based on participant-centered outcomes -- tied back to the common vision. Instead of assessing a system's quality by focusing on procedures and outputs (e.g., numbers served, dollars spent), attention should focus on the outcomes that exist in people's lives.

Cost containment: The system must take clear-cut steps to contain costs -- by using capitated budgets and other "managed care" tools. This can encourage the best use of resources to improve service quality -- or offer some services to people who were previously on the waiting list, or underserved.

Essential Elements of Future Support Systems

1. Vision
2. Self-Determination
3. Flexible Services
4. Personal Advocates/ Brokers & Business Agents
5. Partnerships
6. Unified Funding
7. Outcome Focus
8. Cost Containment

These eight principles clearly distinguish the future support systems for people with developmental disabilities from the way things currently are. They are the key characteristics of ***participant-driven managed long term supports systems.***

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Conclusion

Much has changed in developmental disabilities systems over the past 30 years. And we can fully expect that significant change will take place in our future due to decreasing resources and increasing demand for quality services. Managed care is trumpeted as the solution to this dilemma, but...

There is an alternative to traditional managed care! Together, we can break new ground! We believe that participant-driven managed supports are the way to go. Participant-driven approaches give us a way to hold down costs, while also honoring the preference for self-determination and full participation in community life.

Change entails risk. As systems change, the pressing questions will center on how much risk each player will be willing to take.

If you're a person with a disability or a family member, what risks are you willing to take to participate in a system that gives you greater control and freedom, yet more responsibility and decision-making?

If you're a state or county level administrator, what risk are you willing to take to develop new systems that place people with disabilities in control of the supports they receive?

If you're a service provider, what risk are you willing to take to participate in a more competitive market -- one that rewards flexibility and the best response to what people say they want?

We don't have all the answers. In fact, there are many more questions than answers. In this handbook, we describe the key ingredients of participant-driven managed support systems -- and how they could work. This is only the first step. From here, we hope that you generate further discussions and explorations in your state and your community. These discussions will go a long way toward ensuring the well-being of people with disabilities, and a life in the community directed by their own preferences.

A service system for [people with disabilities] and others in need of support will have to be a system in constant change. It has to be continuously developed, if the 'customers' are not to be left behind and to become hostages of an outdated way of doing things."

Alfred Dam (undated)
Denmark

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Glossary of Terms

Administrative Service Organization (ASO): an entity that does fiscal, legal, and administrative tasks -- often for consumers -- and does not bear any risk.

Business agent: a fiscal intermediary (ASO, see above) who helps participants manage their money and meet administrative and legal obligations (e.g., bookkeeping, payroll, filing and withholding taxes).

Capitation: a method of service financing where the payer pays a fixed amount of money per person to an intermediary to deliver a set of services, whether or not the person uses the services.

Care criteria: a list of allowable services, or standards used to determine what services can be provided.

Carve out: to separately purchase and manage certain services outside the basic managed care package.

Channeling: directing certain recipients to use a particular service provider, thus limiting their choice to lower cost providers.

Community integration: the practice of sharing in community life, involving: (1) physical integration -- the individual actually lives in the community; (2) cultural integration -- the individual exhibits locally valued lifestyles and roles; (3) social integration -- the individual enjoys reciprocal relationships with others in the community; and (4) self-determination.

Exchange networks: programs that support the exchange of goods and/or services between community members with or without disabilities.Go Back

Family support: service and support programs for families providing care at home for children, and sometimes adults, with developmental disabilities.

Gatekeeping/care coordination: a single practitioner is responsible for determining the quality and mix of services a recipient needs *and* receives.

Long-term services and supports: supervision or assistance given to a person with disabilities over time to help the individual complete daily living activities, learn new skills, maintain safety and well-being, or otherwise pursue a normal daily life rhythm. Such assistance typically excludes medical interventions due to injury or illness.

Managed care: strategies that seek to maximize the value of services by controlling their cost and use, promoting their quality and measuring performance to ensure cost effectiveness.

Managed care intermediary: the organization which links the payer to the service providers or recipients.

Managed Care Organization (MCO): the entity which receives a fixed payment to assure that a set of recipients get all services they need; it does not directly provide any services.

Managed Service Organization (MSO): like an MCO except that it does directly provide services.

Medicaid: a federal program created in 1965 to help states pay the medical bills for low-income individuals. The program now has three service areas: 1) health insurance for low-income people, 2) long-term care for seniors and people with disabilities, and 3) specialized services for people with developmental disabilities or mental illness.

Network: a group of service providers affiliated to increase their competitiveness and to assure a clientele.

Participants: direct or indirect recipients of disability services. In participant-driven service systems, these people play a strong role in directing policies and practices related to the delivery of services.

Participant driven managed supports: strategies to administer systems to increase their effectiveness and efficiency, while maintaining a commitment to community integration and self determination.

Personal advocate/broker: a person who provides information, helps participants develop personal plans and budgets, and get needed supports within budget.

Personal assistance: one person assisting another with tasks individuals normally would perform for themselves if they did not have a disability.

Quality assurance: a set of activities intended to ensure minimal safety of service recipients and to foster performance improvements.

Risk: the fiscal uncertainty associated with agreeing to provide all needed services for a fixed payment.

Risk corridor: a risk-sharing arrangement, where a defined range of allowable cost (or benefit) is established above and below the capitation rate.

Self-determination: to make choices and decisions regarding one's chosen lifestyle, independent of undue influence or interference from others.

Service substitution: requires use of a lower cost, but still effective, service in place of a higher cost one.

Utilization review: evaluation by an outside party of the appropriateness, necessity, and/or efficiency of a given service for an eligible recipient.

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Want to learn more? A more comprehensive guide, Managing Our Own Supports: A Primer on Participant-Driven Managed Supports is available from NASDDDS.
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