



Consumer-Directed Supports: An Introduction

2005



What do
consumer-directed supports
mean?





Consumer-directed supports offer people the opportunity to:

- Take personal responsibility for planning and controlling services
- Remain in their homes and communities



"Being able to say when, how and who,
has been very important to my self-esteem...

...People with disabilities are able to direct
their own care and should be given every
opportunity to do so."

Bernadette Thompson

In Other Words...

Consumer-directed supports
offer people **choice** and **control**
over the **type** of services
and **when, where,** and
by whom services are delivered.



What are the principles?

Principles of Self-Determination

Freedom

To determine a meaningful life

Authority

To control budget with assistance, and to purchase supports

Support

To obtain formal and informal resources to achieve goals, meet needs and enhance life

Responsibility

For wise use of public funds and for participating in the community in meaningful ways

Confirmation

Of the important leadership role of individual and family



How has history influenced
consumer-direction
philosophy?

A Little History

1960s ~ 1980s

- Focus on civil rights and independent living

1990s

- Focus on community access, community-based supports for deinstitutionalization, and self-determination

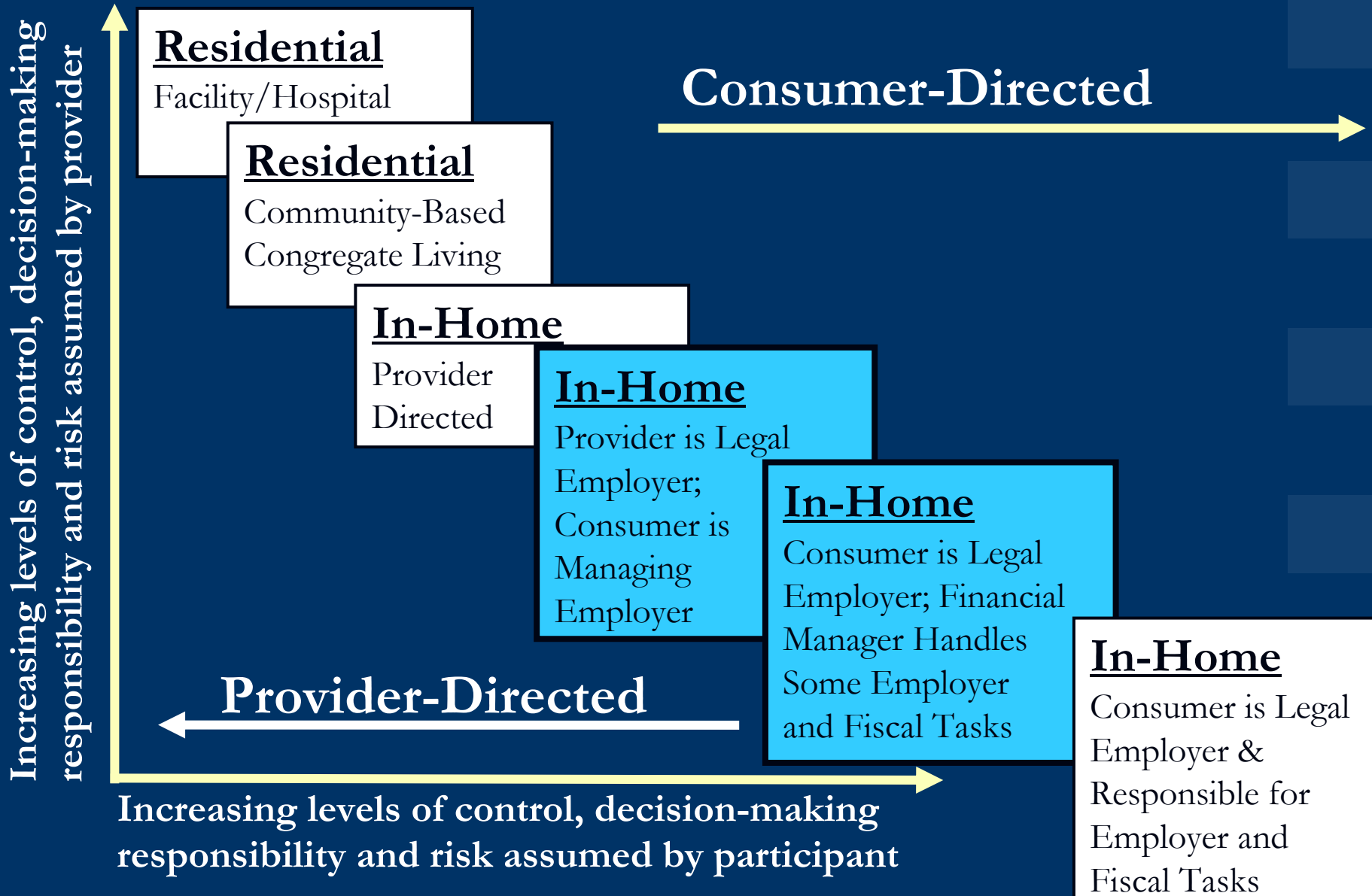
2000s

- Focus on public funding for consumer direction



How do consumer-directed supports fit within the service delivery system?

Support Options





What are the goals of
the program?

Goals of the Program

- To give individuals choice and control over their services, as much as possible
- To be flexible in the use of public funds to meet each individual's needs
- To use public money wisely and appropriately
- To support individuals in their homes and communities



Who can benefit
and participate?



People who have...

- Aging-related care needs
- Chronic conditions
- Developmental disabilities
- Mental health needs
- Physical disabilities
- Sensory disabilities (speech, sight, hearing)

Basic Eligibility

To participate in publicly funded consumer-directed supports a person must first...

Meet the screening and eligibility requirements of the funding source and be approved for services.

Choice

After meeting eligibility requirements, a person may have a choice about what kind of services to receive: facility or residential services, provider-directed services in the home or if available, consumer-directed services in the home.

To make the decision, the consumer must be informed of all the risks and benefits of the choices.



**What are the expected
outcomes for participants?**

Personal Outcomes

Participants...

- Set expectations and goals for their lives
- Manage their own lives
- Have flexibility
- Have control and responsibility
- Hire and direct support workers
- Have independence





**“Consumer-directed supports
would put me back in control of my life.**

**It would have me making the
decisions that I am able, need to
and want to make.”**

Ruth Haines



How do we know that
consumer-directed
supports work?



Consumer-Directed Supports Are Proving Successful

- Independent living programs since 1980s
- Self-determination in MR/DD since mid-1990s
(www.hsri.org)
- Cash and Counseling projects in 14 states started in late 1990s (www.mathematica.org)

These projects show participant satisfaction and improvement in health, relationships, activities and quality of life, at no greater cost.

Consumer-Directed Supports Are Proving Successful

Results from Arkansas' consumer-directed program show that participants...

- Received community-based services at no greater cost to funding sources
- Had high levels of satisfaction with staff reliability, performance and attitude
- Reduced the percentage of unmet needs without compromise to health or safety
- Spent funds appropriately

Arkansas program website: www.independentchoices.com



“Consumer-directed supports give people the right to make decisions for their lives their way.

I've been directing my own supports for 23 years, so I know what it's like.

This is an option that works!”

Jim McCulley



Are there
consumer-directed services in
North Carolina?

Activities in North Carolina

In-Home

Consumer is Employer &
Responsible for Employer and
Fiscal Tasks

- Vocational Rehabilitation's Independent Living Program, Personal Assistance Service
- Division of Services for the Blind (DSB), Personal Assistance Service
 - Designed for individuals who are 18 years of age or older
 - The individual is responsible for:
 - Recruiting, hiring and firing personal assistant(s)
 - Training, directing and managing personal assistant(s)
 - Paying personal assistant(s)
 - Filing and paying state/ federal taxes

[note: DSB files the federal FICA tax]

Activities in North Carolina

In-Home

Consumer is Employer &
Responsible for Employer and
Fiscal Tasks

- Division of Aging and Adult Services, Family Caregiver Program
 - Designed for caregivers of individuals over 60 and for caregivers over age 60 who care for a relative over 18.
 - In consumer-directed option, caregivers:
 - May use vouchers to pay for supports
 - May hire friends or family members as personal assistants

Activities in North Carolina

In-Home

Consumer is Employer &
Responsible for Employer and
Fiscal Tasks

- Centers for Independent Living
 - Provide advocacy and services by and for persons with all types of disabilities
 - Provide supports through consumer-controlled, community-based nonprofits
- First in Families of North Carolina
 - Supports individuals with developmental disabilities and their families to meet self-defined needs
 - Partners with local businesses, citizens and agencies
 - Provides supports through 11 projects with management teams consisting of 75% consumers and/or their families

Activities in North Carolina

In-Home

Consumer is Legal Employer;
Financial Manager Handles Some
Employer and Fiscal Tasks

- **Piedmont Innovations Medicaid Waiver**
 - Developed by Piedmont Local Management Entity
 - Medicaid waiver for individuals with developmental disabilities that has an option for people to choose self-directed services
 - Allows for increased control over services while supporting individuals with employer and financial responsibilities

- **CAP Choice Medicaid Waiver for Disabled Adults**
 - Consumer-directed alternative to the existing Medicaid waiver
 - Allows for increased control over services while supporting individuals with employer and financial responsibilities
 - Pilot projects are currently in Cabarrus and Duplin Counties

Activities in North Carolina

In-Home

Consumer is Legal Employer;
Financial Manager Handles Some
Employer and Fiscal Tasks

- Division of Aging and Adult Services, Home and Community Care Block Grant
 - Designed for people 60 years of age and older and their families
 - In a consumer-directed option, the individual:
 - Determines own needs and supports
 - Recruits, hires, and replaces personal assistant(s)
 - Trains, directs, and manages personal assistant(s)
 - Works with a financial manager to pay taxes and pay personal assistant(s)

Activities in North Carolina

In-Home

Provider is Legal
Employer; Consumer is
Managing Employer

In-Home

Consumer is Legal
Employer; Financial
Manager Handles Some
Employer and Fiscal Tasks

- CAP MR/DD New Focus Waiver
 - NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services is developing a supports Medicaid waiver with consumer-directed options for people with developmental disabilities throughout North Carolina
 - Anticipated implementation is 2006
- Service providers using some consumer-directed features
 - Consumer-directed features are offered in combination with provider-directed features




**What are the differences
in delivery options?**



Differences in Support Options

Increasing levels of consumer
Responsibility for employer-related
duties and fiscal tasks



Residential

Facility/Hospital

Residential

Community-Based
Congregate Living

In-Home

Provider
Directed

In-Home

Provider is Legal
Employer;
Consumer
is Managing
Employer

In-Home

Consumer is Legal
Employer; Financial
Manager Handles
Some Employer
and Fiscal Tasks

In-Home

Consumer is Employer
& Responsible for
Employer and Fiscal
Tasks

- Recruiting and hiring

- Scheduling, training and
supervising

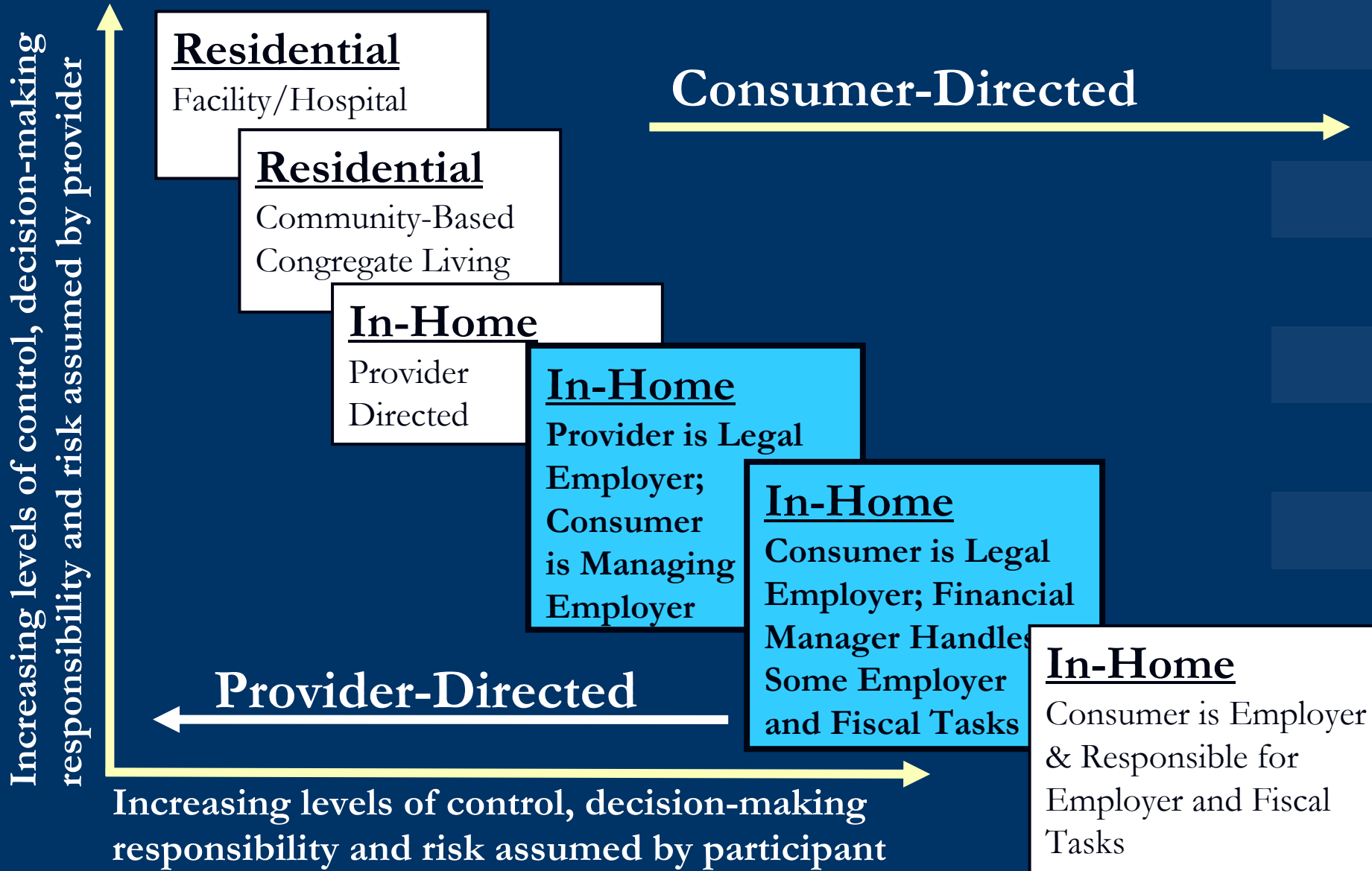
- Payroll

- Working out
problems



**What are the features of
consumer-directed supports?**

Focus on Models





In-Home

**Provider is Legal
Employer; Consumer is
Managing Employer**

In-Home

**Consumer is Legal Employer;
Provider Handles Some
Employer and Fiscal Tasks**



The following slides
show consumer-directed
supports as practiced in
these models of service delivery.

Not all programs or models will have all the features
discussed here.

Features

- Participant-centered plan
- Participant budget
- Participant direction of services
- Team to assist as needed, including members chosen by the participant

In-Home
Provider is Legal
Employer;
Consumer is
Managing
Employer

In-Home
Consumer is Legal
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Manager Handles
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Fiscal Tasks

Participant-Centered Plan

- Evolves from a process led by participant
- Reflects participant chosen life-enriching goals, preferences, needs, strengths, and desired outcomes
- Identifies unpaid and paid people and supports in participant's life
- Identifies services, equipment, and supplies needed
- Specifies time, place and ways to receive services
- Includes information on makes the participant satisfied with services

Example of Questions for Participant-Centered Planning

- What has happened in my life this past year?
- What do I hope this plan will help me accomplish?
- What are my strengths?
- Who am I? What is most important to me?
- What support do I need to maintain the important things in my life?
- What would I change about my life?
- What support do I need to make these changes in my life?

Participant Budget

- Involves participant, case manager and others
- Identifies participant's resources, including funding agency allocations, employment income and other sources
- Outlines how funds will be spent on services, supplies, equipment and other needs
- Receives funding agency approval for public funds
- Follows funding agency rules

Participant Direction Of Services

Within funding source guidelines, the participant decides...

- **Whom to hire** to provide supports.
- **How, when and where** supports are provided.
- What **equipment** and **supplies** to buy.
- From which **supplier, store, or vendor** to purchase some items.



**Who are the team members
and what are their roles ?**



Team Member Roles

- **Participant**
- **Representative** (optional)
- **Case Manager**
- **Advisor** (support broker)
- **Direct Support Worker** (attendant or aide)
- **Financial Manager** (requirement varies with funding source)
- **Federal, state and local government**

Note: Sometimes the same person carries out both the Case Manager and Advisor roles.

A Note about Language

- In North Carolina:
 - Programs are set up differently
 - Not all programs require or offer all team members
 - Not all participants will need or want all team members
 - Different language is used to describe different team member roles.
 - Examples:
 - CAP-Choice: Care Advisor is used to describe a team member that carries out both the Advisor/Support Broker and the Case Management roles
 - Piedmont Innovations: Team members must include a Case Manager and may also include a Support Broker

The Participant

- **Makes decisions about**
 - The best supports to meet needs
 - Services, supplies and equipment
 - The level of help needed from advisor and others
- **Manages direct support workers**
 - Finds, hires and trains people to provide services
 - Decides pay and benefits within approved range
 - Schedules direct support workers
 - Evaluates job performance and replaces workers

The Representative

As an agent of the participant...

- Makes all or just part of the decisions, depending on participant's preference and capacity
- Chosen by the individual
 - For example, the representative can be a trusted friend or a family member
- Cannot be paid for this role
- Cannot be hired to provide other services, such as personal care

Note: Not all participants will choose or need to have a representative.

The Case Manager

As a representative of the funding agency...

- Determines eligibility
- Facilitates development of participant-centered plan and gets the plan approved
- Identifies services and resources
- Maintains official participant records
- Monitors health and safety of participant
- Provides program and budget oversight

The Advisor

As a resource person...

- Assists participant in implementing plan and reviewing monthly expenses
- Identifies community resources
- Teaches participant how to select, train and supervise direct support workers
- Advocates and ensures needs are met
- Communicates with other team members when changes in plan or budget are needed

Note: This role may be carried out by the same person that carries out case management functions.

The Direct Support Worker

As a provider of services and supports ...

- Works under the direction of the participant
- Works when and where the participant chooses
- Uses material, equipment and methods selected by participant

The Financial Manager

As a payroll and check processor . . .

- Serves as the holding agent for the participant's public funds
- Processes checks for workers' wages and other expenses
- Withdraws state and federal taxes from wages
- Gives participant regular updates on budget and expenses
- Files required state and federal documents

Note: Depending on the funding source, a financial manager may or may not be required or available.

The Financial Manager

Depending how the funding source sets up the program, the financial manager may...

- Serve as the “employer of record” on behalf of the participant

or

- Provide supports to enable the participant to be the “employer of record.”

Note: An “employer of record” is an agency or person that handles legally defined employer-related duties.

Financial Manager

As Employer of Record

In-Home

Provider is Legal Employer;
Consumer is Managing
Employer

As an employer of record the financial manager handles employer-related duties, such as...

- Legally employing direct support workers
- Having legal responsibility for supervising, evaluating, and replacing workers
- Handling required paperwork (time sheets)
- Processing pay checks

Note: The participant still has direct involvement in recruiting, hiring, training, scheduling, supervising, and replacing direct support workers.

Participant As Employer of Record



In-Home

Consumer is Legal
Employer; Financial
Manager Handles Some
Employer and Fiscal Tasks

As an employer of record the participant handles employer-related responsibilities, such as:

- Legally employing the direct support worker
- Recruiting and hiring direct support workers
- Supervising, evaluating, and replacing workers
- Handling required paperwork (time sheets)

Note: Financial manager can support participant by providing assistance with hiring and training, managing budget, processing pay checks, and filing legally required documents.

Federal, State And Local Government

As a funder of services and supports . . .

- Provides public dollars to fund services
- Offers training and resources to participants, case managers, advisors, direct support workers and financial managers
- Monitors activities to ensure responsible use of funds
- Monitors safety and well-being of participants

All Team Members

- Understand their roles and responsibilities
- Communicate with one another on a regular basis
- Stay person and family centered
- Support participant as the decision-maker
- Learn and support what participant wants in life
- Stay accessible and available
- Help participant learn about resources and choices
- Maintain responsibility for allocated funds
- Assist participant to meet responsibilities
- Respect confidentiality of information



What protections exist?



Protections

In any program, there are risks.

Consumer-directed supports value the security of...

- Participants
- Direct support workers
- Public dollars

Consumer-directed supports is not about throwing people in deep water without a life preserver!

Protections for Participants

- Resources and training for participants
- Option for participants to choose a representative
- Grievance processes within human service agencies
- Option to return to provider-directed services
- Maintenance of confidentiality
- Monitoring by case managers and advisors

Protections for Direct Support Workers

- Training for participants on how to manage supports
- Hiring agreement with the participant
- State and federal laws and regulations for employers

Protections for Public Funds

- Procedures for determining allocations
- Rules on allowable services and expenditures
- Approval of paid services and budgets
- Requirements for service and financial reporting
- Requirements or availability of financial managers
(depends on fund source)
- Audits of financial records



What are some frequently
asked questions?

Frequently Asked Questions

Question:

Are consumer-directed supports appropriate for individuals with cognitive impairments, dementia or mental illness?

Answer:

Studies have shown that many persons with these disabilities possess the capacity to express their preferences for care and support.

Frequently Asked Questions

Question:

Do consumer-directed supports put individuals with cognitive impairments and other disabilities at risk?

Answer:

Research indicates that consumer-directed supports can assist individuals with cognitive impairments and other disabilities to remain in their homes and communities with no more risk than other types of services.

Frequently Asked Questions

Question:

Do consumer-directed supports models of service delivery include professional expertise?

Answer:

Professional expertise is an essential part of the choices available to people who direct their own supports.

Frequently Asked Questions

Question:

Are individuals who participate in consumer-directed supports likely to misuse funds?

Answer:

People who direct their own supports have been shown generally to have a strong sense of personal responsibility in regard to the services they use and funds spent. Programmatic and funding requirements have protections for appropriate use of public dollars.

Frequently Asked Questions

Question:

Are direct support workers hired within consumer-directed models able to provide quality services to the participant?

Answer:

The direct support workers hired within consumer-directed models can provide high quality services because their training is tailored to the needs and preferences of the individual.

Frequently Asked Questions

Question:

Are consumer-directed supports going to replace other options for receiving services?

Answer:

The long term care service system needs an array of services to support individuals according to their choices and needs, including residential services, provider-directed in-home services and consumer-directed supports.



**What tools are available to
assist individuals and
organizations?**



Consumer-Directed Supports Toolbox

NC Department of Health and Human Services is developing a toolbox of materials.

Audiences:

- Consumers and families
- Direct support workers
- advisors and case managers
- Human service agencies
- Policymakers
- Non-traditional funders
- Policy administrators

Consumer-Directed Supports Toolbox

People and organizations will have tools to...

- Understand consumer-directed supports
- Advocate for consumer-directed supports
- Open doors to provide program options for consumer-directed supports

Consumer-Directed Supports Toolbox

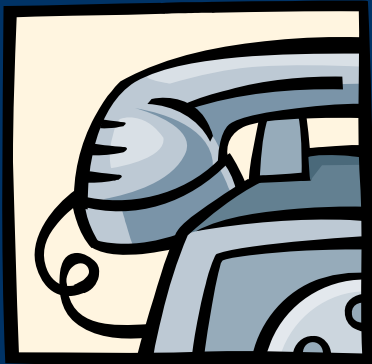
- Brochures
- PowerPoint Presentations
- Participant Manual
- Website materials

What To Do Next

If you are a **consumer or a family member of a consumer who receives services**, ask the case manager or provider for more information on how to be involved in consumer-directed supports.

If you are a **human service professional or provider**, contact the NC Care-Line for more information.

Information Contact



NC Care-Line

800-662-7030

877-452-2514 (TTY)

Care.Line@ncmail.net

www.dhhs.state.nc.us

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The CMS logo features the letters 'CMS' in a bold, blue, sans-serif font. A yellow diagonal line crosses the bottom right of the letters.

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