

What Information Do People Need?

Approaches at the State Level

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Presentation Topics

- What materials were developed
- Who was involved and how
- Why and how decisions were made
- Challenges and how they were resolved

Consumer Directed “Toolbox”

- Developed under Community-Integrated Personal Assistance Services and Supports (CPASS) grant from CMS awarded to North Carolina in 2002
- CPASS in NC was used for infrastructure needs—
 - Materials and education
 - Assessment of barriers in legislation and rules
 - Assessment and strategies to address community inclusion of people with disabilities

Initial Decisions

- Materials would:
 - ❖ Be used by all populations who need long term supports
 - ❖ Appeal to a broad range of people—staff of state and local agencies, policy makers including legislators, consumers and families
 - ❖ NC would draw from other resources around the country as well as the CMS Independence Plus waiver concepts

What State Agencies Were involved?

- CPASS was a Multi-Agency Effort—
 - Office of Long Term Care and Family Services
 - Division of Aging and Adult Services
 - Division of Vocational Rehabilitation
 - Division of Medical Assistance
 - Division of Services for the Blind
 - Division of Services for the Deaf and Hard of Hearing
 - Council on Developmental Disabilities
 - Division of Mental Health, Developmental Disabilities and Substance Abuse Services

Who Else Was Involved?

- CPASS Advisory Committee—primarily consumers and advocates from aging, physical disabilities, mental health, developmental disabilities
- Real Choice Work Group on Consumer Directed Services—including agency staff and stakeholders from all disability groups
- Local Staff Piloting Consumer-Directed Supports in our Aging and Disabled Adults Medicaid Waiver Program (CAP-Choice)
- A Local MHDDSAS Agency with a Carve-out Medicaid Waiver (Piedmont Innovations)
- CPASS Pilot Sites Assessing Local Communities

Contents of Toolbox

- Three powerpoint presentations
- A set of exercises
- A manual for consumers and family members
- Brochures providing a brief introduction to consumer-directed supports
- VHS “Your Choice—An Introduction to Consumer-Directed Care in Aging Services”
- DVD “Choosing the Best...You Decide”
- CD with movie “Metaphors and Mindsets”

Challenges

- Language and concepts for all populations
- Visual appeal, acuity and meaningfulness for different populations
- Politics—internal and external
- Timing—with other grants, other initiatives
- Planning for sustainability

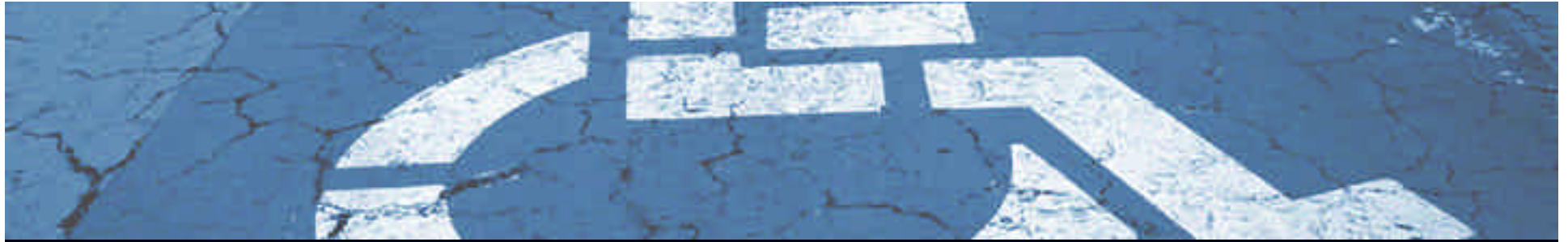
Decisions Made or Changed During the Process

- Development of materials would involve a local subcontractor
- Materials would not necessarily cover some populations to the extent we thought they might
- Compromises were made in content in order to preserve and develop relationships
- Some information moved to speaker notes
- People using the materials could change language to better accommodate different audiences



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

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

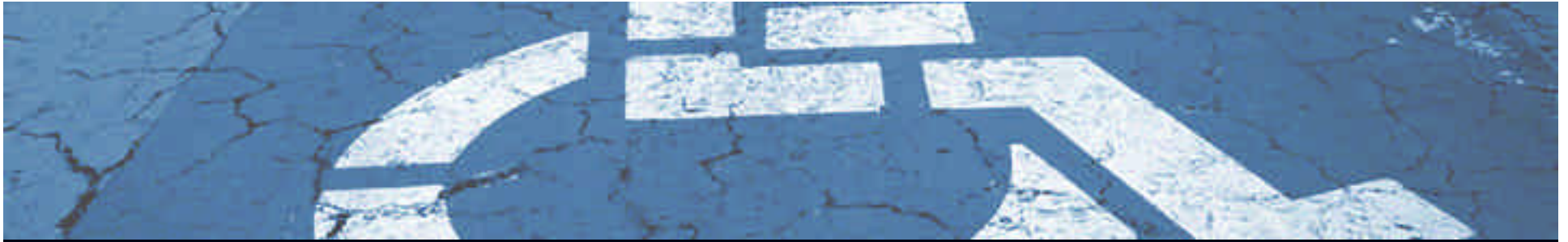
Confirmation

Of the important leadership role of individual and family

Thomas Nerney & Donald Shumway



**Are there
consumer-directed services
in North Carolina?**

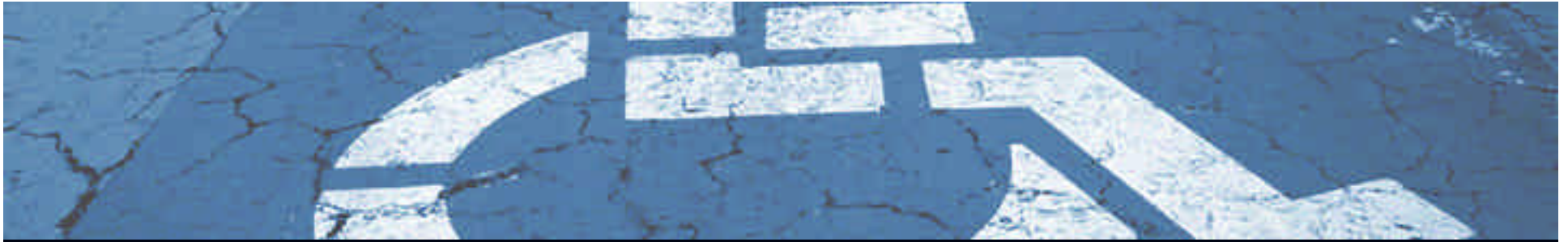


**How do we know that
consumer-directed
supports work?**

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.



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

Support Options

Increasing levels of control, decision-making responsibility and risk assumed by provider

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 Legal
Employer &
Responsible for
Employer and
Fiscal Tasks

Consumer-Directed

Provider-Directed

Increasing levels of control, decision-making responsibility and risk assumed by participant



**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)



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.

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



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!



**What are some frequently
asked questions?**

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 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.

Additional Slides

- Tools to Assist
- Where to Get More Information
- Acknowledgements

Other Challenges

- Timing—
 - ❖ Delay in implementation of waiver— little opportunity to field test
 - ❖ Negotiations made decision-making more time-consuming than anticipated
- Sustainability—
 - ❖ No identified Department staff to continue a cross-Departmental effort, keep materials updated, provide technical assistance, etc.

How Materials Have Been Used

- Presentation to the NC General Assembly
- Used in Consumer-Directed Programs—
with staff and consumers
- Brochures Being Distributed Through NC
Coalition on Aging With the Video
- Materials Used in Training for Nursing
Facility Staff in Conjunction With Nursing
Facility Transition Grant Activities
- Available on Departmental Website

Positive Results

- Products that NC stakeholders “own” and feel proud of
- More collaborative interdepartmental relationships; greater understanding about similarities and differences; greater ability to collaborate on future issues
- Materials seem useful based on reports coming back from local presenters

Thank You

- Website—

<http://www.dhhs.state.nc.us/consumerdirectedsupports/index.htm>

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