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Rutgers Center for State Health Policy
NATIONAL ACADEMY for STATE HEALTH POLICY

June 2004

Connecting the Dots

Community Living Exchange

Funded by Centers for Medicare & Medicaid Services (CMS)

Maryland:
Meeting Summary and Recommendations

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The Community Living Exchange at Rutgers/NASHP provides technical assistance to the Real Choice Systems Change grantees funded by the Centers for Medicare & Medicaid Services.

We collaborate with multiple technical assistance partners, including ILRU, Muskie School of Public Service, National Disability Institute, Auerbach Consulting Inc., and many others around the nation.

This document was developed under Grant No. P-91512/2 from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. However, these contents do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the Federal government. Please include this disclaimer whenever copying or using all or any of this document in dissemination activities.

Introduction

This workshop was organized by the Community Living Exchange Collaborative: A National Technical Assistance Program at the Rutgers Center for State Health Policy for State of Maryland grantees of the Centers for Medicare and Medicaid Services' (CMS) Real Choice Systems Change for Community Living grants. The meeting was facilitated by Susan Reinhard, Rutgers Center for State Health Policy, Michael Morris, National Disability Institute, and Roger Auerbach, Auerbach Consulting, Inc., with support from Marlene Walsh and Yolanda Paskovich, Rutgers Center for State Health Policy.

The Maryland Connect the Dots Workshop was attended by 33 participants representing all of the CMS grantees in that state:

- Aging and Disability Resource Center (ADRC)
- Community-Based Treatment Alternatives for Children (CTAC)
- Family-to-Family Health Care Information & Education Centers (FTF)
- Nursing Facility Transition/Independent Living Partnership (NFTIL)
- Nursing Facility Transition/State Program (NFST)
- Real Choice (RC)
- Respite for Children (RFC)

The grantees were joined by consumers from their advisory committees and state policymakers, including the Maryland Department of Disabilities, and officials from the CMS.

Purpose of Connect the Dots Technical Assistance

Given the complexities of the long-term system of supports and services in the United States, the prospect of developing and implementing enduring systems change is daunting. States face enormous obstacles in overcoming decades of bias that supports and encourages easy, sometimes automatic, access to an institutional setting, but makes in very difficult to access needed public services at home or in a community setting. Since 2001 Congress and the Centers for Medicare and Medicaid Services (CMS) have been investing in states' development of essential infrastructures for sustainable, community-integrated long-term support systems. The work of the national technical assistance providers offers concrete and practical support to grantees challenged by the need to operationalize the goal of community living for people of any age who have a disability or long-term illness.

Guided by a gap analysis and group consensus building process, the "Connecting the Dots" workshop model is designed to help states build a stronger capacity to network, with greater focus on integration and collaboration with each other, with individual participants, state and federal agencies, and national organizations leading advocacy for systems reform. Our objective for this kind of workshop is to create an ongoing mechanism within the state to continue communication, coordination and improved collaboration among key public and private stakeholders involved in systems change activity.

We asked the grantees to be prepared to discuss their greatest challenges to systems change and capacity building and strategies they are involved in to improve individual service choices, systems coordination, and quality that will be sustainable after the grant funding period. The group identified and discussed policy and infrastructure changes that are accelerating sustainable change across systems.

Policy Changes for Sustainable Systems Change

Maryland grantees and consumer advocates have successfully sought several policy changes that can help them sustain systems change that advance community living for all. These policy changes include:

Money Follows the Person (MFP)

Three pieces of MFP legislation passed with overlapping objectives:

1. The Money Follows the Individual Act (HB 478) establishes a conceptual framework for policy and identifies available services. It prohibits the Department of Health and Mental Hygiene (DHMH) from denying an individual access to a home and community-based waiver due to a lack of funding for the waiver services in several different circumstances.

2. The Money Follows the Individual Accountability Act (HB 946) facilitates relocation of nursing facility residents to home and community-based services. It requires DHMH staff to review certain quarterly assessments to identify residents with a preference to live in the community.
   - Information and cross fertilization of community programs is a key on the local level (e.g. CILS outreach to Housing Authorities strengthens collaboration and knowledge of strategic work)

3. HB 752 requires NF discharge planners/social workers to provide information about and referrals to HCBS waiver programs and other long-term supports and services in the community when a resident indicates an interest.
   - Nursing facilities (NFs) are beginning to make referrals rather than the CILS having to enter a NF and initiate contact
   - Residents transitioning from NFs are eligible to access “Living at Home” and “Older Adults” Medicaid Waivers even though they are both closed to community applicants. But does money really follow the person?
   - Over 200 individuals have transitioned from NFs to community

Children and Families

- The Executive Order (01.01.2003.02) on **Custody Relinquishment and Access to Services for Children** recognizes that families must be supported and assisted as they identify and access critical services for children who have significant mental health needs and/or developmental disabilities. The EO created a **Council on Parental Relinquishment of Custody to Obtain Health Care Services** and includes members from State agencies and community stakeholders to address this issue.
- The **State Coordinating Council for Residential Placement of Disabled Children** and the Local Coordinating Councils continue to focus on the State's long-standing concern for children who are placed in residential treatment. Promoting resources to improve services, promoting interagency plans-of-care and coordination are several of the mandates of the Council.
- The **Maryland Caregivers Support Coordinating Council** was created to coordinate statewide planning, development, and implementation of family caregiver support services. One priority of this Council is to help implement the recommendations of the Custody Relinquishment Council for child and adolescent respite care. They will work cooperatively to develop a respite care model for families of children with disabilities as an alternative to custody relinquishment.
- The linkage between these two councils integrates the work of the Respite for Children and Community-Based Treatment Alternatives for Children grants in a unique way as feasibility studies are completed and service models are developed. Any public policy stimulated by the work of these two councils potentially could also benefit the efforts of the Family to Family grant with a mission to enhance the ability of children with disabilities and special health care needs to participate fully in community life.

State Infrastructure Changes

Maryland has made several structural changes that elevate the concerns of older adults and people with disabilities. These changes include:

- The creation of the cabinet level Department of Disabilities offers State of Maryland a unique opportunity to create one single vision and align policy and practice to support it
- The Aging and Disability Resource Center (ADRC) model offers potential to operationalize a vision through single entry on a local level to improve access and coordination of information and services
- The Governor's Commission on Housing Policy offers an opportunity to craft new solutions to affordable housing development coordinated with services

Greatest Challenges for Enduring Systems Change

Facilitated discussion identified key challenges for enduring systems change. These challenges include:

- Fragmented and Inadequate funding (including Medicaid and School funding for children with mental health disabilities)
- Lack of coordination
- Supply of quality providers
- Balance of " Health and Safety Assurances" with consumer-direction in a climate of increasing quality focus in medical model
- Lack of affordable and accessible housing (lack of HUD vouchers)
- States' accountability in relation to satisfying consumer wants and responsibilities. Is government ready to transfer risk/accountability to consumers and families? (dignity of risk)
- Social Ideology vs. Political Reality (e.g. builders' association lobby resist visitability code legislation because they do not want to put nursing facilities out of business)
- Lack of continued funding for peer mentoring and helping people grow and develop
- Epidemic of children's psychiatric disorders
- Cost shifting among agencies to consumers
- Self-interest of agencies and constituents generating policies
- It is perceived that due to socio-economic conditions some consumers of color are excluded from opportunities to voice concerns
- Mental Health and Developmental Disability public policy void for children at all levels of government which has lead to such practice as parents relinquishing guardianship to assure services for child (e.g. absence of "C" Waiver authority for children needing psychiatric residential service in community setting)
- Six state agencies for respite care with twenty-seven chapters of regulations (funding source for service is vulnerable)
- Attitude of presumed competence of families (providers, government, etc.)
- Lack of information to families
- Lack of common vision on process (e.g. eligibility determination)
- Need inter-agency collaboration and political strategies (political will)
- Overcoming turf issues for accountability, oversight, and capacity development
- Lack of infrastructure and funding to improve systems
- Understaffing
- People's plates are full

Development of a "Coherent Systems Framework"

Based on their discussion of achievements and challenges, the participants identified what they need to do is operationalize the CMS Systems Framework for Community Living.

A. Access

- Acknowledging that individuals learn in different ways, consumers need information early, often, and in different formats to avoid the critical pathways to short-term or longer-term institutionalization
- States must be clear about which services consumers want and need and the eligibility to access them
- In order to empower consumers, states need to commit resources to support and enable individuals to easily connect, manage, and control their lives in a community setting
- Information and referral across lifespan

B. Financing

- Money following the person offers more choice through global budgeting
- Individual budgets assume competence
- Consumer-directed systems give individuals more control
- Capitated long-term care systems offers some states cost-effective spending options

C. Services

- Assistive Technology
- Housing and environmental modification
- Transportation
- Employment
- In-home services-recruit, train, reward & retain more individuals to deliver in-home services
- Peer Mentors-deinstitutionalization
- Support for family caregivers
- Support for self-care

D. Quality

- Participant determination
- Provider quality/credentialing
- Accountability for outcomes

Recommendations/Next Steps
Based on participant discussion and subsequent workshop evaluation forms, the participants identified the following recommendations and next steps:

- Establish a work group across all Maryland "Real Choice Systems Change" stakeholders including grantees, select consumers and key stakeholders (i.e. representatives from the newly created Department of Disabilities). Immediate agenda items include: development of common philosophy; how to ask consumers what makes a good system and evaluate the programs based on articulated values; fostering a connection between federal, state, and local agencies' age groups; enhance dialogue and collaboration between newer and more veteran grantees; best practices on critical pathways toward sustainability.
- Establish open dialogue with CMS regarding obstacles implementing consumer-directed programs and other policies.
- Continue to update workshop attendees on activities that are applicable to them, especially best practices with project sustainability.
- Continue to assist developing strategies to reach out to under-served communities and address cultural competency issues.
- Enhance linkages with resources to assist with project development
- Continue to provide relevant information electronically
- Provide samples of consumer surveys
- Help with linkages with CMS policy iterative processes
- Develop evaluation tool for information and data related to sustainability
- Help with evaluation of initiatives
- Facilitate discussion around issues of critical pathways in nursing home diversion and transition
- Focus on improvement of four levels of information flow:
    1. Between Grantees
    2. Between local and state government service delivery systems.
    3. Between public and private not for profit sectors.
    4. Between public sector and consumers.
- Need internal education process that will parallel these grants in relation to the external overseers, stimulating a realignment of the long-term system of support and services and related benefits. Sometimes the flow of information through outreach and education enhances coordination of activities and service delivery. (Peer Mentors are important to reach consumers directly.)

Summary

Grantees believed that the workshop was very valuable for them in many ways:

- They had the opportunity to share information with other grantees about their work plans and accomplishments;
- They had the opportunity to hear the opinions and values of other grantees and key stakeholders on the challenges to developing and implementing enduring systems change;
- They had the opportunity to identify successes already accomplished in supporting community-integrated services for people with disabilities of all ages;
- They jointly identified some needed development of supports to further advance their common goals;
- They agreed that it would be beneficial for them to continue to work on these challenges in a coordinated effort;
- They identified ways ongoing technical assistance could help them achieve their goals; and
- They agreed on next steps to pursue their work in a coordinated manner.

The Rutgers Center for State Health Policy believed that this was a valuable use of resources, especially when there are many CMS grantees in different departments of state government and in the private sector. State and federal finances are limited and must be used so that there is no duplication of effort and strategies and program implementation are coordinated and mutually supportive. We hope this workshop will act as a catalyst for future cooperative efforts among grantees and key stakeholders in the State of Maryland.

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