

A New Approach to Medicaid... “Community First”

Presented by Tom Nerney

Self-Determination:
The Fierce Urgency of Now

National Research & Training Center on Psychiatric
Disability University of Illinois at Chicago

Chicago, IL, April 15-16, 2009

Principles of Self-Determination

■ FREEDOM

The opportunity to choose where and with whom one lives and to organize all important aspects of one's life with freely chosen assistance as needed

■ AUTHORITY

The ability to control some targeted amount of public dollars

■ SUPPORT

The ability to organize support in ways that are unique to the individual

■ RESPONSIBILITY

The obligation to use public dollars wisely and to contribute to one's community

■ CONFIRMATION

The recognition that individuals with disabilities themselves must be a major part of the redesign of the human service system of long-term care

The Country Looks to a Platform of Hope & Change, and Yet...



- Thousands of individuals with disabilities are forced to live in poverty, inhibiting meaningful community life
- Many rely on Medicaid and public benefits that don't supply needed or preferred services/supports (and reinforce impoverishment)
- Health care reform, while welcome, has pitfalls for people with disabilities

The Fierce Urgency of Now

- It's time to address a century's worth of struggle to overcome isolation, stigma, segregation, and the lack of effective services and supports
- It's time to jumpstart a cross-disability movement to reform long-term support for people in mental health recovery, individuals with disabilities, and the aging



What Will it Take?

- A call for the nation's long-term care system to be fundamentally transformed to promote **Community First Whole Health**
- Start by tackling fundamental problems with Medicaid and other public benefits

The Values Driving Reform

Medicaid beneficiaries would be:

- Given a choice of life in the community and opportunities to thrive
 - An end to enforced institutionalization & ineffective, non-recovery-oriented community programs
- Able to meet their unique personal needs and preferences from a full array of community-based options
 - Including “non-clinical” services and supports, such as job, housing, and asset development assistance
- Allowed to control the funding to pay for the services and supports they choose



Is the Impossible Possible?

- Medicaid reform can be good public policy and fiscally sound
- Two core components to guide comprehensive, fiscally responsible reform:
 1. State realignment of resources to advance community participation for all people with disabilities
 2. Federal-level administrative changes to form a single office dedicated to implementing state-level reforms (described more fully in the paper, “*A Perfect Storm*”
http://www.centerforself-determination.com/docs/The_Perfect_Storm.pdf)

The Transformation Plan

- Start by investing \$100 million in up to 10 demonstration states
 - q Demo states expected to completely realign their long-term care systems
 - ✓ Historic realignment would move public dollars out of institutions and into community-based programming and supports
 - Ø Home and community-based services/supports made widely available to all eligible beneficiaries
 - q This investment is less than one tenth of one percent of current Medicaid long-term care spending
 - ✓ Original investment can be easily recaptured through modest nursing home transitions alone
 - Ø A 10% diversion rate for nursing home admissions would return hundreds of millions of dollars to demo states annually

New State Plans

Realigned State Plans must:

- be designed in full partnership between state officials and mental health, disability, and aging leaders
 - partnership throughout Plan creation, implementation, & evaluation
- cover all Medicaid-eligible persons with a disability no matter what the label or prior ineligibility status
- Serve all Medicaid beneficiaries on waiting lists for services and supports
- Provide people with psychiatric and other disabilities and the aging with opportunities to thrive in the community
 - Engage existing organizations by helping them plan to retool their service delivery as needed

New State Plans

- Enable beneficiaries to direct their own community services and supports
- q Provide Medicaid benefit directly to the beneficiary through self-determination programs, including:
 - Fiscal intermediary & brokerage services
 - Person-directed planning & individual budgeting
 - Recovery-oriented services/supports, including supports/services/education from peers



New State Plans

- Address massive unemployment and underemployment of people with psychiatric and other disabilities
 - q SSA would provide demo states with a waiver allowing an adjusted income disregard of approximately \$400/month (where it would be if adjusted for inflation over the last 30 years)
 - q Feds would allow development of special savings accounts that wouldn't jeopardize public benefits
 - Modeled on IDAs and PASS plans
 - q Private income generation would begin the reduction of average per capita costs

A Recovery Medicaid Waiver

A 6-point plan to direct Medicaid funding to recovery-oriented services

■ Policy 1: Alternatives to Psychiatric Hospitalization

- Medicaid to reimburse alternatives including:
 - warm lines
 - peer-run crisis respite (overnight support to avoid the hospital)
 - peer support in ERs (reduce trauma, and provide choice of crisis respite and/or in-home peer support)



A Recovery Waiver

- **Policy 2: Personal self-determination accounts** (as described previously)
- **Policy 3: Person-driven recovery and resilience planning and service evaluation**

National training of peers, families, and providers on person-driven planning:

- Holistic rather than a symptom reduction perspective
- Person in need of help is seen as whole and complex; not diminished or dehumanized
- The sharing of power and responsibility in decision-making
- The recognition of a therapeutic alliance and partnership
- Provider-as-person, not merely a position of authority

A Recovery Waiver

■ Policy 4: Medicaid reimbursement of rehabilitation services

- Interpretive guidelines from CMS to broaden the definition of “medical necessity” (precedent in Michigan)
 - Include “rehabilitative necessity” and “community integration”
 - Would allow Medicaid support for establishing a home (supportive housing), obtaining and keeping a job (supportive employment/career development), and returning to school (supportive education)

A Recovery Waiver

■ Policy 5: Peer support reimbursement by Medicaid

- Medicaid reimbursable recovery-based peer support provided in all states
 - Peer support training developed and implemented by persons with lived experience of mental health recovery
 - Supervision of peer workers conducted by persons with lived experience, similar job experience, plus additional supervisory training



A Recovery Waiver

- **Policy 6: Medicaid Reimbursement of Self-Directed Personal Care Assistants (PCA) in Mental Health**
 - Interpretive guidelines issued by CMS to state Medicaid Authorities detailing how to use PCAs for mental health
 - Draw on experience in Oregon and New York
 - Include activities of community living in the definition of PCA-reimbursable services

Join the Bi-Partisan Call!

- **We, the undersigned, call for a fundamental restructuring of the long-term care system in the United States. The current federal/state Medicaid financed long-term care system is institutionally biased, excessively complex, overly expensive, not reflective of best practice, provider-driven, and inherently unfair.**

<http://www.centerforself-determination.com/docs/Bi-Partisan.pdf>