A New Approach to Medicaid…
“Community First”

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Self-Determination:
The Fierce Urgency of Now

National Research & Training Center on Psychiatric Disability
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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

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The Transformation Plan

- Start by investing $100 million in up to 10 demonstration states

- 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
  - Home and community-based services/supports made widely available to all eligible beneficiaries

- 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
  - 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

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

- 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)

- Feds would allow development of special savings accounts that wouldn’t jeopardize public benefits

- Modeled on IDAs and PASS plans

- 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

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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