Managed Care: Doing It Right
Applying Independent Living Philosophy to Health Care
Assisting State Legislators to Raise Questions and Find Answers

The National Advisory Board on Improving Health Care Services for Seniors and People with Disabilities (NAB)

NAB | NATIONAL ADVISORY BOARD

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Six Principles to Modernize the Health Infrastructure

Six Principles Necessary to Modernize Our Health Care Infrastructure

1. Enhance Self-Care through Improved Coordination
   - Transform America’s health care system from one that focuses on episodic illnesses to one that assists individuals in self-managing their whole health, with the support of providers and communities.
   - Encourage the fundamental and financial investment in physicians to serve as the medical home for patients.

2. Encourage Community Integration and Involvement
   - Coordinate support services, housing, and transportation so people are able to participate in the social, economic, educational, and recreational activities available through community living.
   - Promote data integration, continuity, and coordination of services through the use of health information exchange.

3. Expand Accessibility of Services and Supports
   - Retool programs and regulations which allow people to access the services they need to live independently without creating financial hardship for the family.

4. Uphold Personal Preference
   - Leverage the success of long term service models that promote personal strengths and preferences and preserve dignity of participants.

5. Empower People to Participate in the Economic Mainstream
   - Encourage the employment of people with disabilities and seniors by removing disincentives for people to work and redefine antiquated descriptions of disability.

6. Invest in Improved Technology
   - Invest resources in the continued development of technology that improves individuals’ ability to self-monitor chronic health conditions and live independently.

National Advisory Board — Who We Are

The National Advisory Board on Improving Health Care Services for Seniors and People with Disabilities is composed of distinguished and culturally diverse community advocates, health care experts, and academics who provide guidance and policy recommendations for improving programs and services for seniors and people with disabilities. As a Board, we are people with disabilities; children of aging parents; parents of children and adults with disabilities; and sisters, brothers, spouses, children, and friends of people with disabilities. We represent millions of Americans with disabilities and seniors and their family members, who have struggled with the complexities of our fragmented health care system. Each of us brings a personal perspective to the subject of long term care because each of us has personal experience with it. We, individually and collectively, have worked along with other Americans to overcome the many hurdles to obtain the services we need to live successfully in our communities—hurdles such as the lack of coordination between acute and long term services and supports, antiquated systems and policies, and lack of infrastructure development for
long term services. The National Advisory Board would like to thank Amerigroup Corporation for funding the work on this project. Amerigroup Corporation, headquartered in Virginia Beach, Virginia, improves health care access and quality for the financially vulnerable, seniors, and people with disabilities by developing innovative managed health services for the public sector. Through its subsidiaries, Amerigroup Corporation serves approximately 2.7 million people in Florida, Georgia, Louisiana, Maryland, Nevada, New Jersey, New Mexico, New York, Ohio, Tennessee, Texas, and Virginia, and Washington.

“Declaration of Independence: A Call to Transform Health and Long Term Services for Seniors and People with Disabilities” is a special report produced by the National Advisory Board (NAB). In issuing this report, we call on the principles below to promote independent living and reform our system of care.

SOURCE:
NAB Principles – an Amerigroup product
Current Initiatives That Are Affecting Medicaid Long Term Services and Supports

MEDICAID MANAGED CARE

THE ELDERLY

MEDICAL SERVICES

LONG-TERM SERVICES AND SUPPORTS

COMMUNITY-BASED SERVICES

INSTITUTIONAL SERVICES

WAIVER CONSOLIDATION

INITIATIVES TO PROMOTE CBS

MEDICAID-MEDICARE ELIGIBLE

TYPES OF PLANS

INTEGRATION INITIATIVES

- Advantage
- Special Needs Plans (SNPs)
- Program of All Inclusive Care for the Elderly (PACE)

- Integration Demos
- Financial Alignment

MONEY FOLLOWS PERSON
- ACCA Options
- Health Homes
- Balancing Incentives
- Community First Choice

SOURCE:
Everyone needs to be at the table in the design, implementation, and evaluation of a managed long term services and support program.

There are numerous reasons for meaningfully involving all stakeholders in all phases of the program:

- Including all will better define and meet the needs of people with disabilities
- Sharing the state’s vision for system improvement will educate, inform and promote reform
- Including allow states and their managed care agents to learn how services and supports are currently provided and how services and supports can be improved
- Including allows partnerships to form
- Including partially protects against political backlash
- Reduces anxiety, fear and develops trust

Communication methods for involving stakeholders include:

- Focus groups
- Regularly held meetings
- Work groups
- Public webinars and hearings
- Requests for information
- Publicly posted website information with opportunity for public comment
Assisting People with Disabilities – Doing It Right

People with disabilities should have access to services and supports that they need in order to:

1. Choose who to live with
2. Maintain continuous relationships with family, friends, and other natural supports (communities of faith, social groups, political affiliation, etc)
3. Opportunity to engage in meaningful days, including full and part time employment and/or self-employment with adequate supports, services, and accommodations
4. Afford necessary services and supports
5. Have reasonable access to necessary services and supports from qualified and competent providers
6. Have choice of service and support, including the people who provide them
7. Control and self-direct their daily life and understand the principles of self-determination
8. Have a sense of dignity and security
9. Choose where to live

Doing it right requires state government policies and programs that promote each of these life goals. In addressing the needs of people with disabilities, it is important to consider the unique and diverse needs of issues such as: health and services/supports disparities faced by people due to race, origin, language, and related factors; the need for cultural awareness; the need for cultural competence; and the recognition of the growing diversity of the population. While recognizing and appropriately addressing diversity is required, the overall approach and theme of the NAB is an emphasis on inclusion.
Olmstead – the ADA Supreme Law of the Land

Olmstead Requires Assistance in the Home and Local Community

On June 22, 1999, the U.S. Supreme Court ruled in *Olmstead vs LC* that unnecessary segregation of people with disabilities violates the Americans with Disabilities Act (ADA). Olmstead requires an affirmative obligation by the states to assist people with disabilities to live in their own home and community. Publicly financed services to people with disabilities must be in the “most integrated setting appropriate to” their needs.

Olmstead requires that public service systems help people with disabilities to live in their own home, to pursue employment and education in their community, and to spend time with their families and friends. The most integrated setting appropriate allows individuals with disabilities to interact with non-disabled people to the fullest extent possible.

Olmstead does not force people with disabilities to be served in integrated settings, but in order to make meaningful choices, people must fully understand their options. Informed choice is a major objective and requirement. A person need not wait to be segregated before seeking the protections of the ADA.

To comply with Olmstead, a state may have to change its Medicaid payment policies. States need to formulate a plan for implementation.

DID YOU KNOW?

13 YEARS ago, the U.S. Supreme Court ruled unnecessary segregation of people with disabilities violates the Americans with Disabilities Act (ADA).
Importance of Medicaid for People with Disabilities and Their Families

Medicaid May Be the Single Most Important Federal and State Program for People with Disabilities

The Enrollment Numbers

Of the 58.8 million people enrolled in Medicaid in FY 2008, more than 9 million people qualified due to a disability. 5.6 million of these people (62%) rely only on Medicaid for their coverage while 3.5 million (38%) also had Medicare coverage. People with disabilities account for 15% of the Medicaid population but 42% of total Medicaid spending. People with disabilities on Medicaid have substantial and complex health needs and require long term services and supports. Almost 9 million people with disabilities are under the age of 65 years while 670,000 enrollees are 65 or older on the basis of disability eligibility.

Medicare and Medicaid – the Medicaid-Medicare Eligible Beneficiaries

Nearly 9 million people, including 5.5 million low-income seniors and 3.4 million people with disabilities under the age of 65, are Medicaid-Medicare eligible for and enrolled in both Medicare and Medicaid. Responsibility for health care services for Medicaid-Medicare eligible beneficiaries is divided in complex ways between the two. Half of Medicaid-Medicare eligible beneficiaries are in fair to poor health. 66% have 3 or more chronic conditions. 61% have a cognitive or mental impairment. 86% of people Medicaid-Medicare eligible have incomes below 150% of poverty. People Medicaid-Medicare eligible are 20% of Medicare enrollees but 31% of Medicare spending and 15% of Medicaid. These people have complex but highly varied needs.

SSI and SSDI – Pathways to Medicaid Eligibility

2/3 of Medicaid enrollees who qualify on the basis of disability do so through one pathway – SSI (Supplemental Security Income). Almost all people under age 65 with disabilities who are Medicaid-Medicare eligible receive SSDI (Social Security Disability Insurance). Medicaid administrative data provides little or no information about the disability diagnosis of eligible Medicaid people. SSA (Social Security Administration) can provide parallel data on the SSI eligible people.

Expenditures

Medicaid spends more in total and per person on Medicaid-only enrollees under age 65 who qualify on the basis of a disability than on any other Medicaid population. Medicaid spent in FY 2008 $19,682 per under age 65 Medicaid-only disabled enrollees and $13,835 per under age 65 dually enrolled Medicaid-Medicare disabled enrollees. This compares to $3,025 per Medicaid eligible child and $4,651 per Medicaid eligible adult without a disability. Individuals qualifying for Medicaid on the basis of disability accounted for half of real (inflation-adjusted) growth in Medicaid spending between FY 1975 and FY 2008. Medicaid is the largest payer of mental health services in the United States.

Medicaid is the dominant source of payment for long term services and supports, followed by out-of-pocket payments by individuals and families. Except for short term skilled nursing home care immediately following hospitalization, Medicare plays no role in financing long term services and supports (LTSS). Payments for LTSS represent almost one-third of all Medicaid spending. Most Medicaid LTSS is for institutional care but in recent years states have been “rebalancing” expenditures to home and community based services.
Who Are the Individuals with Disabilities on Medicaid?

“There is no single profile of Medicaid beneficiaries with disabilities.” Most of the individuals qualifying for Medicaid on the basis of disability have co-morbid conditions in addition to their qualifying disability. Co-morbidities of Medicaid-only enrollees qualifying on the basis of a disability include: mental illness, 47%; cardiovascular disease, 38%; and central nervous system diseases, 28%. 45% are diagnosed with 3 or more chronic conditions and account for 75% of Medicaid-only enrollees with disability spending.

What Are Medicaid Long Term Services and Supports?

Medicaid and CHIP Payment and Access Commission (MACPAC) observed: “There is no universal definition of Medicaid long term services and supports (LTSS). In fact, the definitions used by analysts vary.” Further, “little is known about the quality of care received by Medicaid enrollees with disabilities.”

REFERENCE


[Kaiser Commission on Medicaid and the Uninsured. “People with Disabilities and Medicaid Managed Care: Key Issues To Consider.” February 2012, page 2.]


[MACPAC, Report to the Congress on Medicaid and CHIP, March 2012. Pages v, 2, 3, 11, 14, 17, 22, 24, 57, 61]


Medicaid Requirements and State Options — Some Medicaid Basics

Medicaid May Be the Single Most Important Federal and State Program for People with Disabilities

How Does Medicaid Work?
Medicaid is paid for by states and the federal government. The federal share of Medicaid ranges from 50% to 75% of costs. Under some circumstances, the federal matching rate may be up to 90%. The federal government sets minimum eligibility levels for coverage and then states have the option to expand eligibility.

Mandatory Covered Populations — “Categorically Needy”
In order to receive federal financial assistance, states must provide Medicaid to pregnant women and children under certain income levels, caretakers of children under certain income levels, in most states people receiving Supplemental Security Income (SSI), and people residing in medical institutions under certain income levels.

Optional Covered Populations — “Medically Needy”
States can cover certain people determined as “medically needy.” These people have too much money to be eligible as categorically needy but have significant medical needs. If a state has a medically needy program, they must cover pregnant women through 60 day postpartum period, children under age 18, certain newborns, and certain blind people.

Mandatory Services
In order to receive federal financial assistance, states must provide the following services – inpatient hospitals, outpatient hospital, laboratory and x-ray, certified pediatric and family nurse practitioners, nursing facility services, EPSDT (early and periodic screening, diagnosis, and treatment), family planning, physicians’ services, medical and surgical services of a dentist, home health services for those requiring nursing home level of care, nurse mid-wives, services required for complicated pregnancies, and 60 days postpartum pregnancy services.

Optional Services
States may receive federal financial assistance for the following services – prescription drugs, clinic services, inpatient psychiatric services for children, targeted case management, diagnostic-screening-prevention services, rehabilitation services, institutional services for certain individuals with intellectual and developmental disabilities, transportation, dental services, eyeglasses, and podiatry. It’s necessary to remove the institutional bias as we proceed.

Medicaid Policy Obstacles
Another tool in this tool kit identifies some policy obstacles that limit through Medicaid how states can assist people with disabilities and their families.

REFERENCE
Sidebar on Medicaid

Medicare is a nationally administered program to provide health security for seniors aged 65 and over and people disabled and receiving Social Security Disability Insurance (SSDI) or other Social Security payments after a 24 month waiting period for Medicare. Medicare covers 48 million people, including 8 million under the age of 65 years with disabilities. 17% of the Medicare enrolled population are people with disabilities and under the age of 65. The Centers for Medicare and Medicaid Services (CMS) administers the Medicare programs. Private insurance programs have important roles in Medicare program administration.

Medicare has four components:

- **Part A** hospital insurance;
- **Part B** voluntary supplemental physician and “outpatient” health services;
- **Part C** voluntary Medicare Advantage program to receive additional services offered through special health plans; and
- **Part D** voluntary prescription medications.

Program participants pay monthly premiums for Parts B, C, and D.

Medicare generally does not pay for long term services and supports, although there are some services and supports that may be paid for defined “spell of illness” periods, particularly after hospitalizations.

- **A primer on Medicare is available from the Alliance for Health Reform at**

DID YOU KNOW?

Medicare covers 48 MILLION people, including 8 million under the age of 65 years with disabilities.
Medicaid Home and Community Based Services – State Options

Many states have developed home and community based services and supports for people with disabilities through a variety of “waiver” authorities. These are waivers to existing federal legal requirements, requested by the state with the approval of the Centers for Medicare and Medicaid Services (CMS). There are 300 state waiver programs serving 1.2 million people with expenditures exceeding $27 billion.

Waivers include:

- **Section 1115**
  This authority allows states to develop innovative approaches to delivering a variety of health care services to Medicaid recipients. This authority also allows eligibility expansions. States can waive “statewideness” requirements, “comparability of services” requirements, and “freedom of choice of providers” requirements. Income and eligibility standards can be waived.

- **Section 1915b**
  This authority allows states to implement managed care, create benefits that do not have to be available statewide, and to use savings from managed care to purchase services not covered under the state plan.

- **Section 1915c and 1951i**
  The Section 1915c authority allows states to develop home and community based services to individuals who generally require long term care facility level of care. The 1951i authority allows states to develop home and community based services through a state plan amendment.

**Money Follows the Person**

This state option awards the state with enhanced federal financial assistance for 12 months for each Medicaid enrollee transitioned from an institutional facility to a community setting. This option is sometimes referred to as a “re-balancing” initiative. States may also continue and expand the Section 1915j “cash and counseling” program to enhance “consumer-directed” services and supports.

**Community First Choice**

This state option allows states, through the state plan option, to provide statewide home and community based attendant supports and services to individuals who otherwise require an institutional level of care. States choosing this option are given enhanced federal financial assistance.

**State Balancing Incentives Payment Program**

This state option gives states enhanced federal financial assistance to states to increase the proportion of Medicaid long term services and supports dollars for home and community based services and decrease the proportion of dollars for institutional facility services.

**Health Homes**

This state option supports “health homes” or “coordinated primary care-specialized care services to children and adults with chronic conditions.
What Are Long Term Services and Supports?

Long term services and supports are a range of services and supports required by individuals with significant disabilities to live at home with the supports they need, fully participating in their communities, and living with satisfying and meaningful lives. These services and supports are intended to meet personal and health-related needs over a long period of time.

Home and community based services and supports include a range of personal, support, and health-related services provided in the person’s home or community to help the individual live as independently as possible.

More than 10 million Americans need long term services and supports to assist them in life’s daily activities. Roughly half of these people are over the age of 65 and roughly half of these people are under the age of 65 with disabilities. People with long term services and supports needs span all ages and often have substantial acute care needs also. Children with significant disabilities may need services and supports throughout their lives.

States attempt to plan, develop, implement, and sustain statewide, integrated systems that offer a comprehensive set of high quality, evidence-based services and supports that help people and their family caregivers to remain independent and healthy in the community. States mobilize the human, physical, and financial resources necessary to meet these program objectives.

The NAB Approach

The National Advisory Board (NAB) promotes “home and community based services and supports.” The NAB’s approach is defined using six principles: (1) Enhance Self-Care Through Improved Coordination; (2) Encourage Community Integration and Involvement; (3) Expand Accessibility of Services and Supports; (4) Uphold Personal Preference - Leverage the success of long term service models that promote personal strengths and preferences and preserve dignity of participants; (5) Empower People to Participate in the Economic Mainstream; and (6) Invest in Improved Technology.
What Is a Community Based Setting?

For a decade, the federal Centers for Medicare and Medicaid (CMS) has published interim definitions of “community based setting” and “home and community based setting” applicable to Medicaid funding. On May 3, 2012, CMS published another interim definition, with public comments sought. April 2011 was the last previously issued interim definition with requested public comment.

State legislators need to be aware of the controversies involved in defining a “community based setting.” A significant majority of the disability community overwhelmingly accepts the six National Advisory Board (NAB) principles and their application to “community based settings,” consistent with the requirements of the Supreme Court’s Olmstead decision [See tool #5 for a summary of the Olmstead decision.] Some people within the disability community advocate institutional settings for people with the most severe disabilities.

The NAB Approach

Four of the NAB six principles are directly applicable to the definition of a “community based setting” under Medicaid. These are: (2) Encourage Community Integration and Involvement; (3) Expand Accessibility of Services and Supports; (4) Uphold Personal Preference - Leverage the success of long term service models that promote personal strengths and preferences and preserve dignity of participants; and (5) Empower People to Participate in the Economic Mainstream. Any setting considered “community based” should be consistent with these principles.

CMS Issues

Over the past years, four settings have been “automatically deemed” institutional. These are nursing facilities (NFs), institutions for mental diseases (IMDs), intermediate care facilities for people with mental retardation and other developmental disabilities (ICFs/MR), and long term care units of hospitals.

Issues being debated in the May 3, 2012 CMS rules are:

1. Housing and service provision should be de-linked
2. Housing should not be conditioned upon acceptance of services. This requirement is often referred to as “Housing First,” and has received widespread acceptance as a method that promotes independence, choice, and responsibility.
3. With rare exceptions, residents should have unlimited access to food
4. With rare exceptions, residents should have lockable doors from the inside
5. People should not be required to share a unit against his/her will
6. People have a right to decorate his/her room
7. People have a right to freedom of choice on daily living experiences such as meals, visitors, and activities
8. People have a right to opportunities to pursue community activities
9. On the Grounds of an Institution: CMS proposes to exercise a “rebuttable presumption” that a setting is not home and community based for settings that are “located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or disability-specific housing complex.”
10. Issue of consideration - Every person with a disability deserves a range of housing choices and to live in a home of his or her own, including the full rights of tenancy, including a lease
11. Individuals should have a meaningful opportunity to choose from among alternative places to reside
Framework for Assessing LTSS System Performance

High-Performance LTSS System

is composed of five characteristics

- Affordability and Access
- Choice of Setting and Provider
- Quality of Life and Quality of Care
- Support for Family Caregivers
- Effective Transitions and Organization of Care

that are approximated in the Scorecard, where data are available, by dimensions along which LTSS performance can be measured, each of which is constructed from Individual Indicators that are interpretable and show variation across states

SOURCE:
State Long – Term Care Services and Supports Scorecard, 2011
High Performing Long Term Services and Supports System – Diagram, from AARP Public Policy Institute scorecard – see page 23 of 108 pages (exhibit 4) from the report here: http://assets.aarp.org/rgcenter/ppi/ltc/ltss_scorecard.pdf
The Potential Role of Managed Care

Managed Care Can Improve Services and Supports

Managed care offers tools to improve care coordination and quality. The keys are the conditions and structures essential to promote these aims. Managed care is expected to reduce spending, or increase the predictability of spending. Managed care is also expected to improve the delivery and quality of services to overcome fragmented and uncoordinated care. [Kaiser Commission on Medicaid and the Uninsured. “People with Disabilities and Medicaid Managed Care: Key Issues To Consider.” February 2012, pages 1 and 3]

“Experience with and evidence about the impact of Medicaid managed long term services and supports is limited.” [Kaiser Commission on Medicaid and the Uninsured. “Examining Medicaid Managed Long Term Services and Supports Programs – Key Issues To Consider.” October 2011. Page 1]

“Under managed care arrangements, MCOs (managed care organizations) may be able to offer services that would not otherwise be covered as benefits under a state Medicaid plan, if these are effective substitutes for more costly covered services.” [U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Medicaid Financing for Services in Supportive Housing for Chronically Homeless People: Current Practices and Opportunities. February 2012. Page 45]

State Medicaid programs have generally used three managed care arrangements: comprehensive risked based capitation, selected management of targeted populations, and primary care case management. [National Council on Aging. NCOA Friday Morning Collaborative webinar, “Managed Long Term Services and Supports: An Overview of Key Issues and Guiding Principles.” Laura Summer, Georgetown University Health Policy Institute. April 13, 2012.]


“A well designed, accountable Medicaid managed care plan can provide enrollees with high quality, accessible, coordinated care that uses limited state resources efficiently and cost-effectively.” [Health Law and Policy Clinic of Harvard Law School and Treatment Access Expansion Process, for Mental Health America. Medicaid Managed Care, Mental Health Services, and Pharmacy Benefits: An Advocates Tool Kit. September 27, 2011. Page 8]

Managed health plans in the area of mental health improve services by using technology to expand access to treatment; linking members with both primary care and specialized disability providers; developing peer support programs; developing culturally appropriate intake and case management; facilitating access to language interpretation and transportation; increasing screening for depression, substance abuse, and co-morbid conditions for serious mental illness; using sophisticated data systems; training case managers; improving medication adherence; collaborating with communities; working with specialized health organizations; and conducting consumer and family satisfaction surveys. [Medicaid Health Plans of America. Best Practices Compendium for Serious Mental Illness. 2012.]
State Purchaser Objectives

State governments are the purchasers of long term services and supports. Health plans and managed care organizations (MCOs) are the management agents of the state. The state is responsible for the appropriateness, quality, and cost effectiveness of the services and supports.

The objectives sought by a state purchaser of managed care include:

1. Budget predictability (and budget reduction)
2. Improved coordination of services and supports
3. Improved health and reduction of chronic illnesses
4. Electronic health records and integration of health care
5. Market force competition

State legislators must recognize that risk based managed care is a fundamental shift in the way services and supports are financed and delivered. States must carefully and deliberately work through this process of change.

Mileposts for managed LTSS include:

1. Communicate a clear vision for managed LTSS
2. Engage stakeholders to fully gain their insight, ideas, and experiences
3. Use of a uniform assessment tool (appropriate for each person)
4. Structure benefits to appropriately incentivize the right care
5. Include attendant care and/or paid family caregivers
6. Ensure that program design addresses the varied needs of beneficiaries
7. Ensure that programs promote employment and meaningful days
8. Assess the state’s current infrastructure for providing services and supports for people with disabilities, including the role of community based non-profit organizations as well as federally and/or state funded centers for independent living
9. Develop financial incentives to achieve program goals
10. Establish robust oversight/monitoring requirements
11. Recognize the need for LTSS focused performance measurement.
12. Promote full participation in the community
Questions State Legislators Need to Ask

In order to determine a state’s situation in doing what’s right for people with disabilities (see the elements in tool 8), state legislators should ask the following questions:

1. How many people with disabilities reside in the state?
2. In what communities do they reside (number and percent of each community)?
3. What is the composition of their diagnosable disabilities?
4. What are the age categories of people with disabilities?
5. How many are engaged in competitive daily employment?
6. How many receive Supplemental Security Income (SSI)?
7. How many receive Social Security Disability Income (SSDI)
8. How many are Medicare eligible?
9. How many are Medicaid eligible?
10. How many live with their natural family?
11. How many live in the “household of another” and in a “certified medical institution?”
12. How many are supported with Medicaid home and community based services?
13. How many are supported with Medicaid home and community based services by type of state Medicaid option?
14. What does Medicaid spend for people with disabilities by type of residence and type of service?
15. What does the state spend in state general revenue for people with disabilities by type of residence and type of service?
16. Which providers deliver Medicaid financed services for people with disabilities?
   [See tool 15 – Necessary Infrastructure]
17. Which providers deliver state general revenue financed services for people with disabilities?
   [See tool 15 – Necessary Infrastructure]
18. Which other federally financially assisted programs provide information, services, and supports to people with disabilities?
19. What is the general health status of the population with disabilities?
20. What are the most typical co-occurring illnesses and disabilities of people with disabilities?
21. Can these 20 items be cross-tabulated with one another?
In order to determine a state’s situation in doing what’s right for people with disabilities (see the elements in tool 8) and to better understand how services and supports are delivered in the state, state legislators should ask the following questions:

1. What state agency administers the Medicaid program?
2. Do other state agencies administer components of the Medicaid program?
3. What state agency administers the aging (and disability) program?
4. What state agency administers the federally funded Aging and Disability Resource Centers (ADRCs)?
5. Does a state agency administer the federally funded Centers for Independent Living (CIL) programs?
6. What state agency administers the public mental health programs?
7. What state agency administers the federal Mental Health Block Grant program?
8. What state agency administers the public substance abuse programs?
9. What state agency administers the federal Substance Abuse Treatment Block Grant program?
10. What state agency administers the public intellectual and other developmental disabilities programs?
11. What state agency administers the federal Developmental Disabilities State Grant program?
12. What state agency administers the federal Title XX Social Services Block Grant program?
13. Does the state health department administer programs that directly provide services and supports to people with disabilities?
14. Does the state health department administer programs that address the health and wellness of people with disabilities?
15. What state agency administers the federal Maternal and Child Health Block Grant program?
16. What state agency administers the federal Vocational Rehabilitation program?
17. Do the state labor and training programs directly provide services and supports to people with disabilities?
18. Do county governments provide any services to people with disabilities?
19. Who are the state recognized providers of services and supports to people with disabilities?
20. Who are the county recognized providers of services and supports to people with disabilities not already recognized by the state?
21. Does the state recognize the important role played by community based not-for-profit organizations, many of which are consumer and family based?
22. Does the state have the special Medicare initiatives, such as PACE (Program of All Inclusive Care for the Elderly) and SNPs (Special Needs Plans)?
23. If the state has PACE and SNPs initiatives, where are they located and how many people do they serve? What percent of the program beneficiaries have a disability?

We are unable to provide state-specific status of each of these agencies and their structure and responsibilities.
Questions to Ask About Infrastructure

Sources of these possible promising practices are published literature (see tools with resource lists), federal agency studies (see tools with resource lists), and recommendations of individual NAB members.

- **Enhance self-care through Improved Coordination**
- **Transform America’s health care system from one that focuses on episodic illnesses to one that assists individuals in self-managing their whole health, with the support of providers and communities**
- **Encourage the fundamental and financial investment in physicians to serve as the medical home for patients**

**Centers for Medicare and Medicaid Services.** Medicaid-Medicare Eligible Demonstration. January 25, 2012 required “model of care (MOC)” for all enrollees. This MOC should be a starting point for all programs. There are 9 requirements, each has to be “specific” to the targeted population. The 9 requirements are: (1) measurable goals specific to the target special needs individuals; (2) an adequate staff structure having care management roles; (3) an interdisciplinary care team for each beneficiary; (4) a provider network having specialized expertise pertinent to the target special needs individuals; (5) training on the model of care for plan personnel and contractors; (6) comprehensive health risk assessment for each beneficiary; (7) an individualized plan of care having goals and measurable outcomes for each beneficiary; (8) a communication network that facilitates coordination of care; and (9) evaluation of the effectiveness of the model of care.

**Centers for Medicare and Medicaid Services.** Community Based Care Transition Program. Webinar Notes, March 27, 2012. Six States with Program Sites featured. One was the Brooklyn Care Transition Coalition of New York. The Brooklyn program is a collaborative of the Cobble Hill Health Center, Brooklyn Hospital Center, Interfaith Medical Center, and Independent Living Systems. Exploration of the role of Independent Living Systems should occur.

**Oregon – Cascadia Behavioral Health Center, Benton County.** Cascadia Peer Wellness Program. People in recovery are hired through certified programs as Peer Wellness Specialists to perform outreach and mobilization; community and cultural liaison; case management, care coordination, and system navigation; and health promotion and coaching.

**Wrap Around Milwaukee.** Annual Report, 2009. www.county.milwaukee.gov. Search function – Wrap Around. Wrap Around Milwaukee is a system of care with a very comprehensive array of mental health and supportive services organized into a single coordinated network across all child serving systems including mental health, child welfare, juvenile justice, and special education so that youth with complex mental health needs receive all their mental health and supportive services from one program (Wrap Around Milwaukee). Wrap Around Milwaukee is a single case management entity. All funds from participating public agencies are blended into one flexible fund.

**Use of Medicaid’s Rehabilitation Option to finance “assertive community treatment” and “community support teams” for people with serious mental illness.**

**The American Hospital Association has proposed 12 core elements for successful care management of vulnerable seniors, including dual Medicaid-Medicare eligible.** These are hospital based programs focused on seniors with chronic illness. The 12 core elements are (1) complete comprehensive assessment and reassessment, (2) periodic visits, (3) protocol-based planning, (4) person-centered care principles and planning, (5) team-based management centered on primary care, (6) data sharing and integrated information systems, (7) alignment of financial incentives, (8) networks and community partnerships, (9) non-health care services provided (such as transportation), (10) home-based services, (11) center-based “day care,” and (12) cultural competency and equity standards. The AHA identified 10 hospital based “promising models.” One the 10 is the Geriatric Resources program at Wishard Health Systems, Indianapolis, Indiana. Wishard Geriatric
Resources delivers all 12 elements except items #9 and #11 – non-health services provided and “day care.” One the 10 is the Elder Plus program at Johns Hopkins Health System, Baltimore, Maryland. Hopkins Elder Plus delivers all 12 elements except item #6 – data sharing and integrated information systems. One the 10 is the Senior Care Options Program at Commonwealth Care Alliance, Massachusetts. Commonwealth delivers all 12 elements except items #11 and #12 - “day care” and “cultural competence. One the 10 is the Comprehensive Care Management for Seniors Living in Assisted Living sites, nursing facilities, and their homes at Fairview Health Systems, Red Wing, Minnesota. Fairview delivers all 12 elements except items #10 and #11 – home based services and “day care.” One the 10 is the Special Primary Care Center for Chronic Illness at AtlantiCare, Atlantic City, New Jersey. AtlantiCare delivers all 12 elements except items #10 and #11 – home based services and “day care.”


**Mental Health Weekly.** Collaborative Care – Missouri Department of Mental Health Chronic Care Improvement Program and Health Care Homes. Featured program at National Council for Community Behavioral Health annual conference. April 23, 2012. Features program at May 4 Alliance for Health Reform briefing on Primary Care-Behavioral Health Integration.

The Crider Health Center in Missouri started as a psychosocial rehabilitation program then very successfully incorporated clinical mental health services and primary care. [http://www.cridercenter.org/](http://www.cridercenter.org/)

Cherokee Health Center in Tennessee is a national model for integration of mental health and primary care. It is essentially an integrated community health and community mental health center. [http://www.cherokeehealth.com/](http://www.cherokeehealth.com/)

**National Association of State Mental Health Program Directors.** Reclaiming Lost Decades: The Role of State Behavioral Health Agencies in Accelerating the Integration of Behavioral Healthcare and Primary Care to Improve the Health of People with Serious Mental Illness. May 4, 2012. With implementation of a new “Western New York State Care Coordination Program” – New York saw an immediate 46% decrease in emergency department visits per Medicaid enrollee, a 53% reduction in days spent in the hospital, and 92% lower costs for inpatient services, compared to counties without this program.

**NAMI.** Integrating Mental Health and Pediatric Primary Care: A Family Guide. November 2011. NAMI recommends three programs that have successfully integrated mental health and pediatric primary care programs – Cherokee Health Systems, Tennessee; Massachusetts Child Psychiatry Access Project; and North Carolina Center for Excellence for Integrated Care.
Communities are both geographic (urban, suburban, rural, frontier) and demographic (type of disability, income, race, ethnic, and cultural). Medical homes, also known as “patient-centered medical homes” or “health homes” are health care settings that facilitates partnerships between consumers, their families, personal primary care physicians and practices, and specialists to coordinate and/or integrate services and supports. The ongoing relationship with the physician and services and supports team is an integral component. The orientation is on the “whole person.” The patient-centered medical home is discussed in this principle section.

Enhance Self-Care through Improved Coordination – Policy Recommendations

Goal Planning by Systems
States must delineate their goals for transitioning people with disabilities into managed care arrangements or systems. These goals should include enabling individuals with disabilities to live full, healthy, participatory lives in the community. Services should cover the needs of individuals across their lifespan.

Coordination
The Medicaid and CHIP Payment and Access Commission (MACPAC) - “The Secretary (of HHS) and the states should accelerate the development of program innovations that support high-quality, cost-effective care for people with disabilities, particularly those with Medicaid-only coverage. Priority should be given to innovations that promote coordination of physical, behavioral, and community support services and the development of payment approaches that foster their cost-effective service delivery. Best practices regarding these programs should be actively disseminated.”

When a managed care entity coordinates care for individuals whose primary needs are met through long term services and supports, the managed care entity should utilize effective and well-accepted models (i.e., a home health model) that reflects appropriate weight on home and community based services and providers. With appropriate supportive services, inappropriate use of crisis health services can be avoided.

Existing Provider Networks
Plans and programs should include adequate specialists and expertise specific to each disability and chronic condition. Plans and programs should include agencies with long-standing relationships with HCBS waiver participants. Community based organizations play a vital role in ensuring an adequate supply of long term services and supports.

Enrollees should be permitted to retain their existing practitioners for health and long term services and supports to ensure continuity of care for at least one year, regardless of whether these practitioners participate in a managed care program. If a health practitioner is willing to adhere to the plan rules and payment schedules, an individual should be able to continue in that practitioner’s care. Therefore, Medicaid managed care plans should strive to adopt into their provider networks all practitioners and suppliers who currently serve the Medicaid disability population, assuming these providers meet the provider competency and quality requirements adopted by the state.

Attendant recruitment, fair compensation, and retention must be supported by managed care, as consistency of attendant services helps to avert costly secondary medical conditions.
Medications
Individuals with disabilities often require multiple medications and treatments to address their health conditions and need access to a robust and affordable pharmacy benefit. Medicaid managed care plans should be required to adhere to existing access protections in the Medicare Part D program.

Case Management-Care Coordination
12 core elements for successful care management of vulnerable seniors, including Medicaid-Medicare eligible include: (1) complete comprehensive assessment and reassessment, (2) periodic visits, (3) protocol-based planning, (4) person-centered care principles and planning, (5) team-based management centered on primary care, (6) data sharing and integrated information systems, (7) alignment of financial incentives, (8) networks and community partnerships, (9) non-health care services provided (such as transportation), (10) home based services, (11) center-based “day care,” and (12) cultural competency and equity standards.

Care coordination should be linked with independent ombudsmen, 3rd party independent consumer and family monitoring teams, meaningful grievance systems, and a focus on improved outcomes.

Patient-Centered Medical Homes – Core Measures
The U.S. Agency for Healthcare Research and Quality (AHRQ) and its analytical partner, Mathematica Policy Research, identify five “core principles” of patient-centered medical homes (PCMH). These are: patient-centered, comprehensive, coordinated, accessible, and continuous improvement in quality and safety. AHRQ is involved with 27 pilots in 18 states. 60% of the pilots have no evaluation component. 3,302 primary care practices are currently accredited as PCMHs by NCQA (National Committee on Quality Assurance).

Four Foundations of a Patient Centered Medical Home (PCMH) are: (1) Enhanced reimbursement; (2) Expand access through innovation; (3) Aligning case management; and (4) Exchange of meaningful information.

The Commonwealth Fund recommended Core Measures for Evaluating the Patient-Centered Medical Home include emergency department visits, hospitalizations, hospital readmissions, continuity of care, comprehensiveness of care, coordination and integration, whole person orientation, patient-provider communication, and team based care. These are not disability-specific, but should be.

The National Association of State Mental Health Program Directors recommends 9 measures screening for other chronic illnesses in people with serious mental illness. A 10th measure is the availability of “social supports.”

National Quality Forum – National Quality Strategy – endorsed measures and NQS priorities are safer care, effective care coordination, prevention and treatment of leading causes of mortality and morbidity, person and family centered care, supporting better health in communities, and making care more affordable. These are not disability-specific, but should be.

However, the peer-reviewed published evaluation of PCMHs, to-date, are very limited. The U.S. Agency for Healthcare Research and Quality (AHRQ) and its analytical partner, Mathematica Policy Research report that only 14 studies, using 12 interventions, focused on at least three of the five core principles, exist. Only six of these 14 studies were determined “rigorous.” Most of the studies have only examined the impact of adding a care coordinator to a primary care practice. Only one of the 14 studies examines a health care system (Geisinger Health System). There were a limited number of practices in most of these studies. Only a third of the studies collected data from a comparison group of practices. There was high variation in service use and cost in the studies. Most of the patients were “low-risk” patients. Only 5 of the 14 studies looked at the patient experience. AHRQ and Mathematica believe that PCMHs will ultimately significantly improve practice. However, much more evaluation is required.
Electronic Health Records (EHRs)
See principle six – importance of integrated patient-accessible electronic health records (EHRs)

Use of Independent Third Party Consumer and Family Monitoring Teams
Care Coordination and Case Management are fundamental competencies and services offered in well functioning managed care programs. One method for ensuring high quality care coordination and case management is use of independent third party consumer and family monitoring teams.

The Medical Model and the Independent Living or Disability Paradigm
All long term services and supports programs should use the concepts fundamental to the “independent living model”. Traditional managed care programs and health insurance programs rely on the “medical model” whereas the delivery of community disability services and supports use an “independent living” approach. The medical model focuses on strengths of the individual and seeks avoidance of dependence on professional direction. The professional-consumer relationship should be a partnership. The medical model thinks of people with disabilities as sick and needing to be fixed; the independent living model accepts disability as a common part of the human condition and focuses on what the person is able to do, what they desire to do. While the medical model relies on medical professionals to direct what services are needed, the independent living model focuses on barrier removal, self-help, peer supports, consumer control and choice over options and services, and access to medical and professional services as needed. The medical model sees the person with a disability as a “patient,” the independent living model sees the person as an individual, frequently referred to as a “consumer.” The medical model focuses on the improvement in self-care and “activities of daily living,” while the independent living model promotes individual choice over options acceptable to the consumer in supporting integrated community living, which enhance self-care. [See: DeJong, Gerben; expanded by Maggie Shreve and June Isaacson Kailes. Medical Model and Rehabilitation Paradigm and Independent Living and Disability Paradigm. June Isaacson Kailes, Disability Policy Consultant, www.jik.com; 2002.] [See: Krahn, Gloria and Vincent Campbell. “Evolving Views of Disability and Public Health: The Roles of Advocacy and Public Health.” In: Disability and Health Journal. 4 (2011) pages 12-18.]

Through the “participant-directed” approach, training is an important component. There needs to be a commitment to the participant as an employer. When given an option, many individuals with disabilities are choosing to recruit, hire, and supervise their own workers in lieu of agency-provided personal assistants. Directly hired and agency-hired workers frequently have different experiences.

Consumer Centered (sometimes referred to as “Patient” Centered)
See principle #4 – personal preference

Integrated Services and Supports for Medicare and Medicaid Medicaid-Medicare eligible People
Existing programs for Medicare and Medicaid and Medicaid-Medicare eligible people have or should have the following program characteristics: (1) self-directed services, (2) comprehensive assessments to determine needs, (3) person-centered plans of support, (4) multidisciplinary teams, (5) frequent contacts between the program and beneficiaries, (6) decentralized decision making, (7) many home and community based service options, including home based supports (8) family involvement, (9) comprehensive provider networks, (10) flexible benefit packages, (11) consumer protections, (12) technology support of care managers and coordinators, (13) robust data sharing and communication systems, (14) focus on transitions of care between settings, and (15) financial incentives aligned with integrated, coordinated, primary, and preventive supports.
Encourage Community Integration and Involvement - Where This Has Worked

Sources of these possible promising practices are published literature (see tools with resource lists), federal agency studies (see tools with resource lists), and recommendations of individual NAB members.

**Centers for Medicare and Medicaid Services.** Federal Register. Medicaid Program: Community First Choice Option. April 27, 2012. Pages 289-290. Section 441.540: “The person-centered planning process is driven by the individual. The process: (1) includes people chosen by the individual; (2) provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is allowed to make informed choices and decisions; (3) is timely and occurs at times and locations of convenience to the individual; (4) reflects cultural considerations of the individual; (5) includes strategies for solving conflict or disagreement within the process including clear conflict-of-interest guidelines for all planning participants; (6) offers choices of the individual regarding the services and supports they receive and from whom; (7) includes a method for the individual to request updates to the plan; and (8) records the alternative home and community-based settings that were considered by the individual.

The Creating Homes Initiative in Tennessee is a national model for developing a continuum of housing options for people with serious mental illness or co-occurring disorders.

http://state.tn.us/mental/recovery/CHIpage.html Working with local community housing developers and other stakeholders in partnership with seven Regional Housing Facilitators, the program has leveraged to date more than $101 million in federal, state, local, public, private, traditional, and non-traditional funding sources and has successfully created more than 4,600 permanent, safe, affordable, quality, permanent housing options for Tennesseans diagnosed with mental illness and co-occurring disorders.


The CMS April 27, 2012 Community First Choice final rules allow states to provide, at the state’s option, transition costs (rent and utility deposits, first month’s rent/utilities, basic kitchen/bedding needs).

The CMS April 27, 2012 Community First Choice final rules require that services must assist the individual with activities of daily living, instrumental activities of daily living (e.g., shopping cleaning) and health-related tasks.

**Money Follows the Person Program Moving at “Glacial Pace”**

On May 24, Kaiser Health News summarized a report by Mathematica Policy Research that the CMS (Centers for Medicare and Medicaid) Medicaid state option program, Money Follows the Person, has been slow to fully implement. Money Follows the Person supports people who have transitioned back to the community from a variety of institutions. Major reasons for slow delivery are the lack of affordable and accessible housing, lack of community based work force, and not enough life-skills training. Texas has made good progress and California has been very slow because of fragmented and inadequate infrastructure. Nationwide, 14% of the elderly and 10% of people with physical disabilities returned to the institution within a year. The essence of the challenge – states need the CMS dollars to make the investment in the infrastructure; states don’t get the extra federal dollars until people are moved to the community; states can’t move people until they have the infrastructure. Kaiser Health News.

Encourage Community Integration and Involvement – Policy Recommendations

Community participation assists individuals on how best to manage their own lives, with assistance as needed or requested. A health information exchange (HIE) is defined as the mobilization of health care information electronically across organizations within a region, community, health plans, and delivery systems. HIE provides the capability to electronically move clinical information among disparate health care information systems while maintaining the meaning of the information being exchanged. The goal of HIE is to facilitate access to and retrieval of clinical data to provide safer and more timely, efficient, effective, and equitable patient-centered care. HIE is also useful to public health agencies to assist in analysis of the health of the population. HIE is discussed in principle six – improving technology.

Typical of the trend toward encouraging community integration, in the spring of 2012, the U.S. Department of Health and Human Services (HHS) established the Administration for Community Living (ACL).

**Encourage Community Integration and Involvement**

- Coordinate support services, housing, and transportation so people are able to participate in the social, economic, educational, and recreational activities available through community living

**Promote data integration, continuity, and coordination of services through the use of health information exchange**

**Systems Preparedness Assessments**

A fundamental program goal is assisting individuals with disabilities to live full, healthy, participatory lives in the community.

States must perform systems preparedness assessments before deciding when and how sub-populations of people with disabilities should be enrolled in managed care. This is absolutely critical if a state intends to proceed with mandatory Medicaid managed care of people with disabilities. In conducting the assessments, the state must ensure that sufficient time and attention are devoted to ensuring adequacy of service delivery across disabilities and ages, monitoring contractual obligations, assessing quality of services, responding to feedback from participants, and ensuring participant health and safety. If and when a readiness assessment results in such assurances, states should determine whether a phase-in schedule for implementation is warranted.

**Transition From Institutions to the Community; Rebalancing Finances to the Community and the Individual**

States, plans, and programs should promote integration and transition from institutional care to home and community services by providing services and supports necessary to live and work in the community. States planning to enroll recipients of long-term services and supports in managed care plans must include all resources related to institutional programs as well as providers of home and community based services within the plan’s scope of services. In order to increase positive outcomes for service recipients and maximize cost-savings, institutional services and the resources associated with them must not be “carved out” of managed care plans.

Capitation rates must be based on the last three years total expenditures for the covered population and services and use such techniques as risk corridors, risk adjustments, and stop-loss insurance. Any savings must be reinvested for the covered population.

States must use savings realized through system improvements such as care coordination and reduced use of institutional care to address the needs of those individuals waiting to receive services and to expand the Medicaid long term services and supports managed care benefit. Reinvestment strategies should be publicly articulated in the Medicaid managed care application and contract and reflect stakeholder input. These savings cannot be used to address other state budgetary shortfalls or other Medicaid acute care needs. Medicaid fee-for-service payment rates, on which capitation rates may be based, are already too low in many states.
MCOs should provide a transition out program for beneficiaries already in nursing facilities or other long term care facilities. The payment rate for HCBS for these folks should include a transition adjustment for those departing institutional settings.

**Involvement**
States must formally involve stakeholders in the development, design, implementation, monitoring, evaluation and renewal of managed care services, systems, and contracts. Key stakeholders include beneficiaries, their chosen representatives, families, service providers, advocates, and other impacted groups.

States should establish a panel of qualified consumer advisors independent of any plan, including individuals with disability expertise, to advise the state, relevant managed care plans, providers, and consumers of their rights and obligations.

**Quality Measurement to Encourage Community Integration**
The Medicaid and CHIP Payment and Access Commission: “The Secretary (of HHS), in partnership with the states, should update and improve quality assessment for Medicaid enrollees with disabilities. Quality measures should be specific, robust, and relevant for this population. Priority should be given to quality measures that assess the impact of current programs and new service delivery innovations on Medicaid enrollees with disabilities.”

Before implementing managed care of long term services and supports, the state must develop and have in place a comprehensive quality management system that continuously gathers, evaluates, and monitors performance data of contractors and subcontractors. Independent third party consumer and family monitoring teams should be formed and utilized as part of the quality management system to perform on-going evaluations and assessments of the effectiveness of managed care in supporting beneficiaries in living full, healthy, participatory lives in their communities. Quality management data must be transparent and readily available to the public.

States should adopt qualitative data metrics on the managed care entity’s ability to coordinate acute and post acute care, as well as the full complement of Medicaid waiver services, including home and community based services and supports. For instance, managed care plans must be able to demonstrate the ability to provide quality services and attain high consumer satisfaction levels. Managed care plans should routinely report their performance using such metrics. Failure to reach a certain quality threshold should result in meaningful enforcement action by the state to correct the problem. Results must be shared with stakeholders and the general public within reasonable time frames to allow for outside analysis and evaluation.

The dearth of measures to assess the quality of LTSS is of great concern and reinforces a belief that including LTSS for people with disabilities in integrated coordinated demonstrations is premature. Until valid reliable quality measures are adopted, states should not turn over responsibility for those services to private entities. States should “include data by disability type about unmet needs, delays in service, and utilization of services.”

**State Government Expertise**
The state must provide strong administration and oversight of the managed care system, particularly when mandatory managed care is implemented. The state must employ sufficient qualified staff with experience in addressing the needs of individuals with disabilities. The state must obtain regular input from stakeholders. The state’s responsibility for day-to-day oversight of the managed care delivery system must be clearly delineated in managed care contracts.

**States Should Fully Implement the Medicaid Community First Choice State Option**
individual; (2) provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is allowed to make informed choices and decisions; (3) is timely and occurs at times and locations of convenience to the individual; (4) reflects cultural considerations of the individual; (5) includes strategies for solving conflict or disagreement within the process including clear conflict-of-interest guidelines for all planning participants; (6) offers choices of the individual regarding the services and supports they receive and from whom; (7) includes a method for the individual to request updates to the plan; and (8) records the alternative home and community based settings that were considered by the individual. The Community-First Choice Medicaid state plan option is intended to provide home and community based attendant services, assist with activities of daily living and health-related tasks through hands-on assistance, supervision, and/or cueing. States are encouraged to fully implement the Community First Choice program.

The CMS April 27, 2012 Community First Choice final rules allow states to provide, at the state’s option, transition costs (rent and utility deposits, first month’s rent/utilities, basic kitchen/bedding needs).

The CMS April 27, 2012 Community First Choice final rules require that services must assist the individual with activities of daily living, instrumental activities of daily living (e.g., shopping cleaning) and health-related tasks.

**Electronic Health Records (EHRs)**
See principle six – importance of integrated patient-accessible electronic health records (EHRs)

**Portability Across State and County Boundaries**
There should be portability of Medicaid eligibility with current benefit packages, portability of Vocational Rehabilitation supports, and portability of HUD Section 8 vouchers across county lines and across state lines.
Expand Accessibility of Services and Supports - Where This Has Worked

Sources of these possible promising practices are published literature (see tools with resource lists), federal agency studies (see tools with resource lists), and recommendations of individual NAB members.

The Arc recommended national model – State of Michigan, Medicaid Policy Manual, new section 17 – “Additional Mental Health Services” - definition of medical necessity. 2.5.A. MEDICAL NECESSITY CRITERIA Mental health, developmental disabilities, and substance abuse services are supports, services, and treatment:

- Necessary for screening and assessing the presence of a mental illness, developmental disability, or substance use disorder; and/or
- Required to identify and evaluate a mental illness, developmental disability, or substance use disorder; and/or
- Intended to treat, ameliorate, diminish, or stabilize the symptoms of mental illness, developmental disability, or substance use disorder; and/or
- Expected to arrest or delay the progression of a mental illness, developmental disability, or substance use disorder; and/or
- Designed to assist the beneficiary to attain or maintain a sufficient level of functioning in order to achieve his goals of community inclusion and participation, independence, recovery, or productivity.

*These are only a small component of the policy.

HHS ASPE report – Illinois Medicaid definition of medical necessity for people with serious mental illness - SERVICE INITIATION CRITERIA (must meet all of the following):

1. The individual has indicated their agreement with the need for and choice of this service modality and has been actively involved in the development and implementation of the treatment plan.

2. The individual’s severity/complexity of symptoms and level of functional impairment require this service, as evidenced by:
   a. The individual presents minimal risk of danger to self or others;
   b. The individual has significantly impaired role functioning and skill deficits that adversely affect at least two of the following areas and that can be expected to improve through intensive, curriculum-based, short-term skills training in a facility setting:
      i. management of financial affairs
      ii. ability to procure needed public services or other community support services
      iii. socialization, communication, adaptation, problem solving, and coping
      iv. activities of daily living, including personal care; meal preparation; maintaining housing; accessing social, vocational, and recreational opportunities in the community; and establishing or modifying habits and routines
   v. self-management of symptoms or recovery
   vi. concentration, endurance, attention, direction following, and planning and organization skills necessary to progress in recovery
   c. The nature of the individual’s impairment and/or skill deficits can be effectively remediated through focused skills-training activities that prepare the individual to apply new skills in their personal living environments (e.g., home, neighborhood, school, and work) and relationships (e.g., roommates, family, friends, neighbors, landlords, and co-workers).

Expand Accessibility of Services and Supports
Retool programs and regulations to allow people to access the services they need to live independently without creating financial hardship for the family
d. The individual’s current assessment identifies the specific skill deficits that will be addressed through focused skills-training.

e. Individual has a composite Level of Care Utilization System (LOCUS) score equating to Level of Care 3 or higher. [These are only a tiny component of the complete policy.]

Community First Choice Final Rules: On April 26, 2012, CMS (Centers for Medicare and Medicaid Services) announced, and on April 27, final rules were published in the Federal Register to implement the Medicaid state plan option to provide home and community based attendant services. The purpose is to assist with activities of daily living and health-related tasks through hands-on assistance, supervision, and/or cueing. States are encouraged to fully implement the Community First Choice program.
Expand Accessibility of Services and Supports – Policy Recommendations

Comprehensive and Range of Services and Supports

[See principle one on coordination and continuity]
[See principle one on provider networks]
[See principle four on choice of provider]

States’ managed care systems must be able to accommodate the wide range of service and support needs of the disparate segments of the population of people with disabilities. The provider network must have adequate numbers of experienced and qualified providers of primary and specialty health care, behavioral health care, and long term services and supports, including home and community based services, so that participants can obtain care without excessive travel or unreasonable delays in scheduling appointments. Choice of provider is a key factor in ensuring quality of care, especially for the disability population, which tends to develop close and long-lasting relations with providers who come to understand the uniqueness of the particular needs of people with disabilities. If health care and long term services and supports are financed and administered separately, systems must ensure coordination and continuity of care across systems.

States should require managed care systems for people with disabilities to cover the full range of services and supports needed to address the diverse needs of people with disabilities on an individualized basis across the life span. The benefit package should build upon existing services and supports needed by beneficiaries to live in the community, including services for acquiring, restoring, maintaining, and preventing deterioration of function or acquisition of secondary disabilities. Information about the benefits and any limitations imposed on the benefits should be readily available to the public.

Where such providers are not within a reasonable travel distance of beneficiaries, travel to these physicians should be subsidized by plans.

Medical Necessity

Definitions of Medical Necessity must be completely publicly transparent and meet each individual’s goal for community inclusion and participation, independence, recovery, and productivity.

All health care services and supports provided through managed care arrangements must be accessible to people with disabilities and must be provided in the most integrated setting appropriate to the needs of the individual. States must monitor managed care plans to guard against adverse selection of beneficiaries with especially high and expensive needs.

Adhere to Rights and Non-Discrimination Requirements

Managed care systems must fully inform enrollees with disabilities (and their families or chosen representatives) of their rights and obligations under the plan, as well as the steps necessary to access needed services. The information should be made available before enrollment deadlines. The information should be provided in multiple concise, understandable, and accessible formats (for enrollees with disabilities as well as those with limited English proficiency), and every effort should be made to avoid multiple submissions to enrollees, particularly submissions which are inconsistent and create confusion and uncertainty.

Grievance and appeal procedures that safeguard individual rights under the provisions of the managed care plan and all applicable federal and state statutes should be established that take into account physical, intellectual, behavioral, and sensory barriers. Individuals should have access to independent entities for assistance in navigating these procedures.
The state, managed care plans, and contracted providers must ensure that there is full compliance with the Americans with Disabilities Act (ADA) and Rehabilitation Act non-discrimination provisions and the requirements for physical and programmatic access. This includes accessible health care facilities, diagnostic, and therapeutic equipment, and all health care settings considered public accommodations. All facets of a state’s managed care program must also comply with the U.S. Supreme Court’s Olmstead decision, which upheld the ADA’s integration mandate.

The state should establish a panel of qualified consumer advisors, independent of any plan, to advise consumers on their rights and obligations. Grievance and appeal procedures should be established that take into account physical, intellectual, behavioral, and sensory barriers to safeguarding individual rights under the provisions of the managed care plan, as well as all applicable federal and state statutes. The procedures should authorize a state agency to make final decisions overruling the refusal of a plan to provide services.

**Third Party, Independent, Consumer, and Family Operated Teams**

Independent ombudsmen should be available to help beneficiaries. Third party, independent, consumer, and family directed consumer satisfaction monitoring teams should be funded. The teams focus on documented dissatisfaction and regularly meet with health plans to resolve areas of dissatisfaction.

National Empowerment Center. Sara Plachta-Elliott and Jonathan Delman. Consumer-Led Evaluation Teams: A Peer-Led Approach to Assessing Consumer Experiences with Mental Health Services. June 2009. Consumer-Led Evaluation Teams are operated independently by consumers and/or family members and evaluate mental health programs by learning about the experiences of program clients. As of 2009, at least four programs operated across the nation – Consumer Quality Team, Maryland; Consumer Quality Initiatives, Massachusetts; Consumer Satisfaction Team, Philadelphia; and Vital Voices for Mental Health, Milwaukee, Wisconsin. There are two core features of consumer-led evaluation teams: collect consumer feedback through face-to-face peer-to-peer interviews and strong emphasis on provider and funder accountability using regularly scheduled meetings with senior authorities. There are two primary reasons to interview consumers – evaluate the program and make sure the respondent’s needs are being addressed.
Uphold Personal Preference – Where This Has Worked

Sources of these possible promising practices are published literature (see tools with resource lists), federal agency studies (see tools with resource lists), and recommendations of individual NAB members.

- Uphold Personal Preference
- Leverage the success of long term service models that promote personal strengths and preferences and preserve dignity of participants

See the “Policy and Advocacy Recommendations” section for a complete list of 10 Center for Health Care Strategies milestones for managed LTSS. April 13, 2012. One of 10 was financial incentives to achieve program design. The Money Follows the Person initiative was cited as an example.

“Participant-Directed Services” allow program participants to exercise choice and control over the LTSS that they need to live as independently as possible at home. Participants can hire/fire and manage individual paid workers (such as home health aides, personal care attendants, homemaker/chore workers, and other paid worker) of their choosing, rather than being assigned workers from an agency. Participants may also be given a set budget allowance to pay personal aides and purchase goods and services such as assistive technologies, home modifications, personal care supplies, transportation, and other supports recognized as serving to meet disability-related functional needs. The first approach is called the “employer authority,” and the second approach is called the “budget authority.”

States should expand and/or implement participant-directed options that, at minimum allow the individual to manage monetary allowances roughly equivalent to what would be spent for traditional home and community-based services. These allowances would be used to hire and fire personal attendants and aides and/or purchase goods and services (such as assistive technologies, transportation, home modifications). Enrollees may alternatively choose agency delivered services. As of November 2011, there were 298 Participant-Directed Services programs in the U.S., with at least one program in every state. Total enrollment was 810,000 people with 59% of participants in California. The Affordable Care Act (ACA) expands this model through the “Community First-Choice” authority. [Arkansas Department of Human Services; Doty, et al; National Resource Center for Participant-Directed Services.]
Uphold Personal Preference – Policy Recommendations

The intent of this principle is to leverage the success of functionally based, community living long term service and support programs and/or models that promote personal strengths and preferences.

Managed care for people with disabilities must be based—to the maximum extent possible—on individual choice, person-centered planning, and consumer self-direction which includes personal budgeting and oversight of one’s direct services and supports. These are strategies that have been piloted by the Centers for Medicare and Medicaid (CMS) in coordination with selected states for several years with very positive results.

People with disabilities, like all people, strive to live safely, live well, and with maximum independence. Services should not be determined by an individual’s physical or mental health status or functional capacity. The individual’s needs, experiences, and preferences are core to every aspect of policy design. Meaningful communication and input at all levels are key elements.

While consumer choice is the ideal, in a recent NASDDDS-HSRI study, only 41% of consumers with intellectual and developmental disabilities chose where they live; only 37% chose their roommates; and 45% had “no” input into selecting their case managers.

Participant-Directed Options

States should expand and/or implement participant-directed options that, at minimum allow the individual to manage monetary allowances roughly equivalent to what would be spent for traditional home and community based services. These allowances would be used to hire and fire personal attendants and aides and/or purchase goods and services (such as assistive technologies, transportation, home modifications). Enrollees may alternatively choose agency delivered services.

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All states should use the CMS Community First Choice Option definition of “person centered planning.”

Consumer Centered (sometimes referred to as “Patient” Centered)

Throughout the health care system, one sees the need to be “patient centered.” In disability, the field uses “consumer centered” and “consumer directed.” A bridge between acute health care and independent living services and supports is the consumer (patient) centered concept. The Institute for Patient and Family Centered Care defines patient and family centered services and supports as an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, consumers (patients), and families. The concept re-defines relationships in health care. Practitioners recognize the important roles that families play in ensuring health and well-being. Emotional, social, and developmental supports are integral components of health care, promoting wellness, dignity, and control. There are four core concepts of consumer (patient) and family centered services and supports are respect and dignity, information sharing, participation, and collaboration.
**Assistance to Families**
Families should receive the assistance they need to effectively support and advocate on behalf of people with disabilities. If appropriate for the individual, state policies should permit payment to family members and informal caregivers for providing services and supports.

**Self Determination**
People with disabilities, including people with mental and intellectual disabilities, should make their own life decisions. Life decisions should not be made for them by medical professionals or governmental entities. In the mental illness field, mandatory treatment and outpatient and civil commitment are never appropriate, except when a court of law determines that there are immediate and serious dangers to self or others. Adequate and appropriate services, consumer directed and controlled, available on a voluntary basis, will substantially reduce the circumstances leading to possible situations of danger.

**The Dignity of Risk**
The “Dignity of Risk” concept means respecting each individual’s autonomy and self-determination (or dignity) to make choices for himself or herself. Consumers have the right to make their own health care decisions, even if health care professionals believe these choices endanger the person’s health or longevity. Risks are allowed given the need for dignity and meaning. This is not the equivalent to encouraging recklessness. The disability field disagrees within the field about degrees of safety vs consumer choice. The concept of “dignity of risk” promotes and allows prudent risk taking.

**Advance Directives, Including Psychiatric Advance Directives**
Psychiatric advance directives allow people to legally document in advance their choices about future services and supports. SAMHSA- Consumer Bill of Rights and Responsibilities- Final Report: “Give patients the opportunity to refuse treatment and to express preferences about future treatment decisions…. Discuss the use of advance directives – both living wills and durable powers of attorney for health care with patients and their designated family members. Abide by the decisions made by their patients and/or their designated representatives consistent with the informed consent process.”

**Enrollment**
Many people with disabilities eligible for Medicaid are members of subpopulations that are complex, require significant services and devices, and are often among the programs’ most vulnerable enrollees. Managed care programs need to demonstrate capacity to meet these complex needs. Within managed care programs, program participants need choice, including choice of existing practitioners for health and long term care services to ensure continuity of care.
Empower People to Participate in the Economic Mainstream – Where This Has Worked

Individual Placement and Support (IPS) supported employment helps people with severe mental illness work at regular jobs of their choosing. Although variations of supported employment exist, IPS refers to the evidence-based practice of supported employment.

Dartmouth University has an IPS center and is coordinating sites around the country. http://www.dartmouth.edu/~ips/

U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Federal Financing of Supported Employment and Customized Employment for People with Mental Illnesses: Final Report. February 2011. Four states were analyzed for their recent success and experience with implementing supported employment (SE) programs, partially financed with Medicaid. The states were Illinois, Kansas, Maryland, and Washington. The rehabilitation and targeted case management Medicaid options and the Section 1915 HCBS options finance individual supports that are partially related to employment goals. Maryland also authorizes Medicaid “buy-in” for people with disabilities who work.

United Cerebral Palsy. The Case for Inclusion, 2012. May 2012. Just nine states have at least one third (33%) of individuals with ID/DD working in competitive employment. These states are Alaska, Connecticut, Delaware, Maryland, Michigan, Oklahoma, Pennsylvania, Vermont, and Washington.

Sources of these possible promising practices are published literature (see tools with resource lists), federal agency studies (see tools with resource lists), and recommendations of individual NAB members.
Empower People to Participate in the Economic Mainstream –
Policy Recommendation

- Empower People to Participate in the Economic Mainstream
- Encourage the employment of people with disabilities and seniors by removing disincentives for people to work and redefine antiquated descriptions of disability

The intent of this principle is also to include re-employment and promote and utilize an array of work-incentive means, including the effective use of assistive technology. Assistive technology is the focus of principle six.

For non-elderly adults with disabilities, employment is a critical pathway toward independence and community integration. Working age enrollees must receive the supports necessary to secure and retain competitive employment. For those capable of work among beneficiaries with disabilities, Medicaid managed care must provide the services and supports they need to gain or maintain competitive, integrated employment. Working-age enrollees must receive services and supports needed to gain and maintain employment as an integral component of improved health, wellness, and independence with a preference and presumption of competitive, integrated employment.

Employment goals include self-employment. States should continue to provide “Medicaid buy-in” opportunities to those who would otherwise meet the Medicaid eligibility threshold if they were not employed.

Employment rates for people with disabilities are dismissal. Even for people with intellectual and other developmental disabilities who are employed, only 52% of employed individuals earned at or above the state’s minimum wage. [see NASDDDS-HSRI report]

Affordable Care Act Increase in Health Insurance Coverage

The Patient Protection and Affordable Care Act (ACA) strengthens employment opportunities for people with disabilities and economic participation by people with disabilities, by expending health insurance coverage. Health insurance coverage, beginning January 1, 2014, will expand by:

a. All individuals under the age of 65 with incomes at or below 133% of the federal poverty level (FPL), regardless of disability or health condition, may qualify for Medicaid and CHIP (Children’s Health Insurance Program), at state option. The Supreme Court modified the ACA requirement as a state option. The law allows the first 5% of income to be disregarded, thus, one may see 138% of the federal poverty level as the cited eligibility baseline.

b. Individuals without an offer of affordable employment-based coverage, regardless of disability or health condition, can obtain private health insurance through health insurance exchanges, by:

c. Adults over the age of 18 with incomes 133-400% of FPL will be eligible for cost-sharing and premium subsidies.

d. Children under the age of 18 with family incomes 133-400% of FPL will be eligible for either CHIP or premium subsidies.

e. Individuals not otherwise eligible for other coverage who earn up to 400% of FPL may receive premium tax credits, provided in advance, in order to purchase health insurance through the exchanges.

f. Individuals without an offer of affordable employment-based coverage and incomes above 400% of FPL may obtain health insurance through the exchange.

g. Consumers have the option of enrolling in COBRA or the exchanges at the time of the loss of employer coverage.

h. It appears that individuals at or below 100% of the federal poverty level, residing in states that do not expand Medicaid eligibility, may receive federal income tax credits for the health insurance exchange premiums they pay.

[HHS Poverty Guidelines: 2011: one person under the age of 65, $11,702; four person household, $23,201]
Medicaid Assists with Employment Support in Some States

The rehabilitation and targeted case management Medicaid options – and the Section 1915 HCBS options – serve to fund individual supports that are partially related to employment goals. For example, Maryland also authorizes Medicaid “buy-in” for people with disabilities who work.

States vary widely in their commitment to integrated employment. Overall, the findings from a 2010 analysis of employment data suggest that a grim employment situation for individuals with disabilities continues. State and federal policy do not consistently prioritize employment.

There is no preference for integrated employment in Medicaid-funded services, and state Medicaid agencies have limited involvement in employment initiatives. At the core of the problem is the lack of resources currently devoted to addressing employment for people with disabilities.

Supported Employment is defined as a mainstream job in the community, pays at least the minimum wage, work setting includes people who don’t have a disability, service agency provides ongoing support, and is intended for people with the most severe disabilities. The IPS (Individual Placement and Support) model of supported employment is defined as client choice regarding timing, competitive employment, team approach, work incentives planning, ongoing support, and individual preferences are important. IPS is not widely available to people with serious mental illness that need them. The reason is primarily due to the difficulties in financing these services. In many states, Medicaid will pay for some portion of these employment services, but not all. Financing is the key barrier.

In a study of Massachusetts’s use of Medicaid waiver services, members with the greatest unmet need were significantly less likely to be working; 10 to 22% of non-working members thought they would be able to work if needs were met. The findings suggest that meeting unmet needs for disability-related health care services may result in modest increases in employment.
Invest in Improved Technology – Where This Has Worked

Sources of these possible promising practices are published literature (see tools with resource lists), federal agency studies (see tools with resource lists), and recommendations of individual NAB members.

Examples of the use of universal design (UD) in the built-environment, examples of health plans paying for assistive technology, and examples of the use of integrated electronic health records to improve consumer involvement and health will be cited.

Gray, Jennifer A.; Jennifer L. Zimmerman; and James Rimmer. “Built Environment Instruments for Walkability, Bikeability, and Recreation: Disability and Universal Design Relevant?” In: Disability and Health Journal. 5 (2) April 2012. 87-101. The article recommends the King County, Washington “Active Community Checklist,” an urban area use checklist that includes promoting built environment access for people with disabilities.

Kitchener, Martin; Terrence Ng; Hyang Yool Lee; and Charlene Harrington. “Assistive Technology in Medicaid Home and Community Based Waiver Programs.” In: The Gerontologist. Vol 48, No 2, 181-189, 2008. Assistive technology (AT) is a service option under the Medicaid 1915 © HCBS waiver program. The majority of AT is paid for by personal funding. In 2002, 50,380 people with disabilities received durable medical equipment (DME) through HCBS waivers, 43,683 people with disabilities received AT devices through HCBS waivers, and 31,169 people with disabilities received home modification through HCBS waivers.

RESNA – Nell Bailey May 24, 2012 memo to Clarke Ross – Assistive Technology and State Medicaid programs. Many of the state AT programs refurbish used equipment (AT, DME, and computers) and make them available to individuals with disabilities that can’t afford the technology otherwise. In a couple of states (Kansas and Vermont), they are working with state Medicaid to provide reused equipment. Kansas: ATK provides quality used devices through two efforts. KEE is a reuse partnership between Kansas Health Policy Authority and ATK. Through KEE, eligible Kansans can get quality, refurbished durable medical equipment such as manual and power wheelchairs, patient lifts, electronic hospital beds, shower chairs, communication devices, and other health devices. For Vermont, go to http://atp.vermont.gov/get-at-stuff and scroll down to the bottom of the page to see what they are doing and what’s covered.

The concept of “Meaningful Use” appears as a 2009 component of the HHS Health Information Initiative work. The concept has legal standing with the ARRA (American Recovery and Reinvestment Act of 2009) (PL. 111-5) financial incentives to health providers for the meaningful use of certified electronic health records (EHR). ARRA invests dollars to create a national health information infrastructure. Physicians and medical practices have to show that the EHR is being “meaningfully used” to improve patient care and outcomes. In Mental Health Weekly. “Illinois, Kentucky Moving Forward with Health Information Exchanges.” April 23, 2012. Behavioral health is integrated in health information exchanges in Illinois and Kentucky. These states were featured at the 2012 National Council for Community Behavioral Health annual conference.
Invest in Improved Technology – Policy Recommendations

- **Invest in Improved Technology**
- **Invest resources in the continued development of technology that improves individuals' ability to self-monitor chronic health conditions and live independently**

Living independently in the community includes the promotion and support of access to the technology through means to be developed, including funding, loans, tax credits, tax deductions, fees, and insurance coverage.

**Access to Assistive Devices and Technologies**

Participants in managed care must have access to durable medical equipment (DME), prosthetics, orthotics, supplies, and assistive devices and technologies that are needed to function as independently as possible. Access to these devices and related services must be based on diagnosis and individual need determined through qualified evaluation by appropriate professionals. Periodic assessments must be performed in order to ensure that specialized equipment facilitates maximum function and independence and does not exacerbate the participant’s condition with recurrence or development of secondary disabilities. It is imperative that such specialized equipment be evaluated in order to create maximum independence and avoid exacerbating the participant’s condition with recurrence and or a secondary issue.

“Covered services should include professional assessments of beneficiaries needs for such technology (durable medical equipment, prosthetics, orthotics, supplies, and assistive technologies), as well as set-up, maintenance, and user training.

Assistive technology is defined by the Assistive Technology Act of 1998 as “any item, piece of equipment, or product system….that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.” In 2003, it was estimated that 25.6% of mobility AT users (2.5 million out of 9.8 million) were covered under Medicaid. Assistive technology (AT) is a service option in the Medicaid 1915 © HCBS waiver program. In 2002, 63% of HCBS waiver programs included AT, with Medicaid HCBS waivers paying the following AT supports: 50, 380 (durable medical equipment); 43,683 (AT devices); and 31,169 (home modifications). (page 184).

Some of the states favored AT spending for persons with intellectual and other developmental disabilities, to the exclusion of persons who are elderly or physical disability.

The usability of medical diagnostic equipment almost always requires another person’s intervention, usually in the form of a medical provider who operates, or oversees the operation of, the equipment. Design standards and staff training are linked. Staff should receive information and training on working with consumers with disabilities and their families, with a particular emphasis on communication and program access and the use of accessible equipment. Disability Rights Education and Defense Fund. Letter to Office of Technical and Informational Services, United States Access Board: Proposed Accessibility Standards for Medical Diagnostic Equipment. June 8, 2012.

**Electronic Health Records – Integrated, Patient-Accessible Mechanisms**

The concept of “Meaningful Use” appears as a 2009 component of the HHS Health Information Initiative work. The concept has legal standing with the ARRA (American Recovery and Reinvestment Act of 2009) (PL. 111-5) financial incentives to health providers for the meaningful use of certified electronic health records (EHR). ARRA invests dollars to create a national health information infrastructure. Physicians and medical practices have to show that the EHR is being “meaningfully used” to improve patient care and outcomes. Federal ARRA financial incentives are not made to community based non-profit organizations, community mental health and substance abuse programs, and many other settings important to persons with disabilities. Integrated, patient-accessible, electronic health records (EHRs) must be fully used in all settings.

Using information more effectively can assist improvements in organizing, financing, and delivering health care and associated supports. From the consumer perspective, health IT (information technology) can be a critical encourager of safer, more effective, and more reliable
services and supports, as well as promoting greater consumer engagement to stimulate more positive consumer experiences and better health outcomes. Health IT and HER should be assessed against four goals — (1) supporting the partnership between consumers, their families, and their services and supports team; (2) improving the coordination of services and supports; (3) increasing health equity; and (4) enabling new payment and delivery models.

A health information exchange (HIE) is defined as the mobilization of health care information electronically across organizations within a region, community, health plans, and delivery systems. HIE provides the capability to electronically move clinical information among disparate health care information systems while maintaining the meaning of the information being exchanged. The goal of HIE is to facilitate access to and retrieval of clinical data to provide safer and more timely, efficient, effective, and equitable patient-centered care. HIE is also useful to public health agencies to assist in analysis of the health of the population.

**Global Universal Design and the Built Environment**

All long term services and supports programs should fully meet Universal Design (UD) standards as developed by the Global Universal Design Commission. UD includes assistive technology as a component.

The built environment may be defined as “human-made structures that may facilitate or impede an individual’s ability to be physically active.” “Recommendations for new and revised built environment instruments include more focus on specific disability populations, incorporation of all Universal Design principles, as well as attention to psychometric quality and measurement specificity.”

In the “Final Report: Center of Development Expertise (CODE) for Accessibility Task Force Recommendations and Actions.” October 4, 2011, the Assistive Technology Industry Association announced its interest and commitment to overcome “the significant number of obstacles that face the development community in achieving accessible products and applications which have a direct result in employment success for persons with disabilities.” Hardware and software developers lack technical knowledge related to accessibility but support integrating accessibility, interoperability, and usability into the entire development cycle. Funders, managers, providers, and non-profits involved in long term services and supports should actively engage and finance developers working through the Assistive Technology Industry Association.
FMAP – Federal Medicaid Assistance Percentage by State

Federal share of Medicaid spending (FMAP) varies by state
Statutory Federal Medical Assistance Percentages, FY 2012

NOTE: Rates are rounded to nearest percent. These rates will be in effect Oct. 1, 2011 – Sept. 20, 2012.
## Medicaid Managed Care Carve-Outs Status

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<td><strong>Total</strong></td>
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<td>17</td>
<td>16</td>
<td>12</td>
<td>5</td>
<td>15</td>
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**NOTE:** 36 states contract with MCOs. Not all states responded to this question
SOURCE: KCMU/HMA Survey of Medicaid Managed Care, September 2011
Will It Save the States Money?

A state can save money while achieving its objectives of promoting and supporting community living and inclusion of people with disabilities and their families. Per person spending for home and community based services is less than for institutional services. A focus on the most cost-effective ways to meet life objectives of people with disabilities is a helpful way of dealing with the issues of how much it will cost the state and whether it will save the state money.

Cost-Effective Home and Community Based Services (HCBS) may be defined as:

1. On an individual basis: for a given individual to achieve a given outcome, HCBS are equally or less costly than institutional services.
2. On a program basis, in aggregate, total long-term services and supports (LTSS) program costs are equal or less when HCBS are offered than when only institutional services are available.

Analyses consistently document that on an individual basis, HCBS are more cost-effective than institutional services. Total program analyses are more complicated.

Surveys consistently document that most individuals prefer to receive long-term services and supports (LTSS) in their own homes and other community settings instead of nursing facilities.

States are shifting Medicaid spending on LTSS from institutional to HCBS, a process known as “rebalancing.”

Experience using Medicaid HCBS for people with intellectual and other developmental disabilities teaches:

1. In terms of quality of life and changes in adaptive behavior, there is substantial evidence that institutional services are not effective
2. Trends toward smaller service settings are consistent with people’s well-being
3. Adults report good quality of life outcomes while living with family
4. Medicaid expenditures are much lower on average for adults in family-based settings
5. By shifting from ICF/MR (Intermediate Care Facility for People with Mental Retardation) to HCBS, average real dollar per person annual expenditures for Medicaid long term services and supports decreased by 21% between 1993-2009.
6. Increased Beneficiaries for People with ID/DD have driven Medicaid LTSS expenditures for people with ID/DD

In examinations of HCBS across the nation, lessons learned include:

1. States with well-established HCBS programs contained costs better than states with low HCBS
2. On average, per person, one year HCBS is half the cost of a year in a nursing facility
3. HCBS expansion increases short-term spending but may cut long-term spending — the so-called “woodwork” situation — more people enroll
4. More people were served at equal or lower total costs

Financing strategies used by states to increase home and community-based services while decreasing nursing facility spending within budget stability include: Global budgets

1. Money Follows the Person
2. Nursing Home Bed Buy Backs
3. Expansion of Home and Community-Based Alternatives
4. Capitated managed LTSS
5. Pay the same reimbursement rate regardless of setting
6. Reward health plans for appropriate transitions to the community
7. Partnership with long term insurance payers
8. Tactics are within a government-wide vision and plan, using data to monitor implementation

Using statistical models applied to Medicaid LTSS spending over a 15-year period, estimates that gradual rebalancing, by roughly 2% a year, can reduce spending by about 15% over 10 years.

One concept of doing it right is to produce the most cost-effective results, consistent with the Olmstead Supreme Court requirements and the goals to assist people with disabilities achieve their life goals. Cost-effective interventions that improve health and enhance community based independent living will ultimately save the state money.

Roughly 5% of Medicaid beneficiaries use more than half of Medicaid expenditures each year. 20% of people Medicaid-Medicare eligible accounted for more than 60% of the combined Medicaid and Medicare spending for the Medicaid-Medicare eligible population. Cost-effective strategies include more personalized services and supports while people still live in their home, health promotion and prevention interventions, emergency room and repeat emergency room prevention, carefully planned transitions between health care settings, and more effective care coordination (such as patient-centered medical homes and health homes; see note below).

REFERENCES
Center for Health Care Strategies. “Medicaid Rate Setting Strategies To Promote Home and Community Based Services.” May 2012
Commonwealth Fund. [Rebecca Adams, CQ Healthbeat Associate Editor] “Potential Solutions to High Costs in Medicaid Explored.” June 4, 2012
Note on Patient-Centered Medical Home (PCMH) or Health Home: The peer-reviewed published evaluation of PCMHs, to-date, are very limited. The U.S. Agency for Healthcare Research and Quality (AHRQ) and its analytical partner, Mathematica Policy Research report that only 14 studies, using 12 interventions, focused on at least three of the five core principles, exist. Only six of these 14 studies were determined “rigorous.” Most of the studies have only examined the impact of adding a care coordinator to a primary care practice. Only one of the 14 studies examines a health care system (Geisinger Health System). There were a limited number of practices in most of these studies. Only a third of the studies collected data from a comparison group of practices. There was high variation in service use and cost in the studies. Most of the patients were “low-risk” patients. Only 5 of the 14 studies looked at the patient experience. AHRQ and Mathematica believe that PCMHs will ultimately significantly improve practice. However, much more evaluation is required.[Mathematica Policy Research. “Implementing the Patient-Centered Medical Home: Remaining Questions and Challenges.” June 7, 2012 Center on Health Care Effectiveness Forum.]
Medicaid Policy Obstacles to Assisting People with Disabilities in Meeting Their Life Objectives

State legislators will be told that Medicaid policy restricts some programs states may want to develop using Medicaid. Constituents will tell state legislators about their life goals and how Medicaid gets in the way to achieving these goals. There are policy experts and advocates that can assist state legislators bridge some of these gaps and obstacles. There are creative ways to address Medicaid policy obstacles.

Existing Medicaid Programs contain many barriers to assisting people with disabilities achieve their life objectives. Medicaid policy barriers include:


4. While some Medicaid services are delivered in Permanent Supportive Housing, such services are rarely provided in integrated housing settings. [U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Medicaid Financing for Services in Supportive Housing for Chronically Homeless People: Current Practices and Opportunities. February 2012. Page 39]

5. Despite the severity of disability and need for assistance, being employed and earning a regular income over the poverty level usually makes people with disabilities non-Medicaid eligible in most states.

6. Most states do not simultaneously provide, in combination, the Medicaid rehabilitation option, personal assistance option, case management option, and the variety of other allowable home and community based services and supports.

Some states have overcome these obstacles, as outlined in other tools.
# Medical Model vs. Independent Living Model

## Independent Living and Traditional Paradigms*

This chart compares traditional approaches to medical and vocational rehabilitation services with the consumer-driven, independent living approach.

<table>
<thead>
<tr>
<th>Definition of the problem</th>
<th>Medical Model and Rehabilitation Paradigm</th>
<th>Independent Living or Disability Paradigm</th>
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<tbody>
<tr>
<td></td>
<td>physical or mental impairment; lack of vocational skill (in the VR system); lack of abilities</td>
<td>dependence upon professionals, family members, and others; it is the attitudes and environments that are hostile and need fixing</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Locus of the problem</th>
<th>medical Model and Rehabilitation Paradigm</th>
<th>Independent Living or Disability Paradigm</th>
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<tbody>
<tr>
<td></td>
<td>in the individual (individuals are sick and need to be “fixed”)</td>
<td>in the environment; in the medical and/or rehabilitation process itself; disability is a common part of the human condition</td>
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<tr>
<th>Solution to the problem</th>
<th>Medical Model and Rehabilitation Paradigm</th>
<th>Independent Living or Disability Paradigm</th>
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<tr>
<td></td>
<td>professional intervention; treatment</td>
<td>1. civil rights and advocacy</td>
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<td></td>
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<td>2. barrier removal</td>
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<td>3. self-help</td>
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<td>4. peer role models and peer support</td>
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<td></td>
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<td>5. consumer control over options and services</td>
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<table>
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<tr>
<th>Social role</th>
<th>Medical Model and Rehabilitation Paradigm</th>
<th>Independent Living or Disability Paradigm</th>
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<tbody>
<tr>
<td></td>
<td>individual with a disability is a “patient” or “client”</td>
<td>individual with a disability is a “consumer,” “customer,” or “user” of services and products</td>
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<table>
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<tr>
<th>Who controls</th>
<th>Medical Model and Rehabilitation Paradigm</th>
<th>Independent Living or Disability Paradigm</th>
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<tbody>
<tr>
<td></td>
<td>professional</td>
<td>“consumer” or “individual”</td>
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<tr>
<th>Desired outcomes</th>
<th>Medical Model and Rehabilitation Paradigm</th>
<th>Independent Living or Disability Paradigm</th>
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<td></td>
<td>maximum self-care (or “ADL” — activities of daily living); gainful employment (in VR system)</td>
<td>independence through control over ACCEPTABLE options for everyday living in an integrated community</td>
</tr>
</tbody>
</table>

*paradigm: a model, example, archetype

**RESOURCE:**
Developed by Gerben DeJong in 1978; adapted/expanded by Maggie Shreve and June Isaacson Kailes, Revised 1/2002

Medical Model vs Independent Living Available at: http://www.jik.com/ilcpara.html
The Medical Model and the Independent Living or Disability Paradigm

All long term services and supports programs should use the concepts fundamental to the “independent living model.” Traditional managed care programs and health insurance programs rely on the “medical model,” whereas the delivery of community disability services and supports use an “independent living” approach. The medical model uses a focus on physical or mental impairment and lack of abilities. The independent living model focuses on strengths of the individual and seeks avoidance of dependence on professional direction. The professional-consumer relationship should be a partnership. The medical model thinks of people with disabilities as sick and needing to be fixed; the independent living model accepts disability as a common part of the human condition and focuses on what the person is able to do, what they desire to do. While the medical model relies on medical professionals to direct what services are needed, the independent living model focuses on barrier removal, self-help, peer supports, consumer control and choice over options and services, and access to medical and professional services as needed. The medical model sees the person with a disability as a “patient;” the independent living model sees the person as an individual, frequently referred to as a “consumer.” The medical model focuses on the improvement in self-care and “activities of daily living,” while the independent living model promotes individual choice over options acceptable to the consumer in supporting integrated community living, which enhance self-care. [See: DeJong, Gerben; expanded by Maggie Shreve and June Isaacson Kailes. Medical Model and Rehabilitation Paradigm and Independent Living and Disability Paradigm. June Isaacson Kailes, Disability Policy Consultant, www.jik.com; 2002.] [See: Krahn, Gloria and Vincent Campbell. “Evolving Views of Disability and Public Health: The Roles of Advocacy and Public Health.” In: Disability and Health Journal. 4 (2011) pages 12-18.]

Through the “participant-directed” approach, training is an important component. There needs to be a commitment to the participant as an employer. When given an option, many individuals with disabilities are choosing to recruit, hire, and supervise their own workers in lieu of agency-provided personal assistants. Directly hired and agency-hired workers frequently have different experiences.
State Agencies Serving People with Disabilities

**National associations of state agencies**

- [Association of Maternal and Child Health Programs (AMCHP)](www.amchp.org)
- [Association of State and Territorial Health Officials (ASTHO)](www.astho.org)
- [Council of State Administrators of Vocational Rehabilitation (CSAVR)](www.rehabnetworking.org)
- [National Association of Councils on Developmental Disabilities (NACDD)](www.nacdd.org)
- [National Association of State Alcohol and Drug Abuse Directors (NASADAD)](www.nasadad.org)
- [National Association of State Directors of Developmental Disabilities Services (NASDDDS)](www.nasddds.org)
- [National Association of State Mental Health Program Directors (NASMHPD)](www.nasmhpd.org)
- [National Association of States United for Aging and Disabilities (NASUAD)](www.nasuad.org)
National Organizations of State Legislators

As you seek ideas and guidance on how other state legislators are approaching and thinking about the issues of home and community based services for people with disabilities, the following national organizations of state legislators may be helpful.

- **American Legislative Exchange Council**
  http://www.alec.org/

- **Council of State Governments**
  http://www.csg.org/

- **National Black Caucus of State Legislators**
  http://www.nbcsl.org/

- **National Conference of State Legislatures**
  http://www.ncsl.org/

- **National Hispanic Caucus of State Legislators**
  http://www.nhcsl.org/

- **Women in Government**
  http://www.womeningovernment.org/
What’s Happening in the Other States

State-by-State Programs List

Alabama

- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states, in order from 1st to 5th were Minnesota, Washington, Oregon, Hawaii, and Wisconsin. The bottom five states, in order from 51st to 46th were Mississippi, Alabama, West Virginia, Oklahoma, and Indiana.

- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for choice of setting and provider, in order from 1st to 5th were Alaska, Washington, Minnesota, Vermont, and Oregon. The bottom five states for choice of setting and provider, in order from 51st to 46th were Mississippi, Alabama, Delaware, South Dakota, and Tennessee.

- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for support of family caregivers, in order from 1st to 5th were Oregon, Washington, Arizona, Minnesota, and Iowa. The bottom five states for support of family caregivers, in order from 51st to 46th were Oklahoma, Alabama, West Virginia, New York, and Montana.


Alaska

- National Academy of State Health Policy and Health Resources and Services Administration. Six State Teams for Medicaid-Safety Net Learning Collaborative Selected. April 10, 2012. The states were Alaska, Iowa, Maryland, Maine, Minnesota, and Texas.

- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for choice of setting and provider, in order from 1st to 5th were Alaska, Washington, Minnesota, Vermont, and Oregon. The bottom five states for choice of setting and provider, in order from 51st to 46th were Mississippi, Alabama, Delaware, South Dakota, and Tennessee.

- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for quality of life and quality of care, in order from 1st to 5th were Alaska, North Dakota, Hawaii, Minnesota, and Iowa. The bottom five states for quality of life and quality of care, in order from 51st to 46th were Mississippi, Kentucky, Oklahoma, Tennessee, and Maine.


- United Cerebral Palsy. The Case for Inclusion, 2012. May 2012. States are rated on “four key aspects of a high functioning Medicaid program” – (1) participation in their communities, (2) have satisfying lives and valued social roles, (3) have sufficient access to needed support and control over that support to contribute to the lifestyles they desire, and (4) live in safe and healthy environments. Only 15 states supported a large share of families through family supports. More than a quarter of a million people (268,000 nationwide) are on waiting lists for home and community based services. Just nine states have at least one third (33%) of individuals with ID/DD working in competitive employment. These states are Alaska, Connecticut, Delaware, Maryland, Michigan, Oklahoma, Pennsylvania, Vermont, and Washington.
American Samoa

Arizona

- On March 14, CMS (Centers for Medicare and Medicaid) announced 23 additional Community based Care Transitions Program (CCTP) sites. CCTP targets Medicare patients with risk of hospital readmissions. CCTP are community based organization-acute care hospital partnerships focused on providing community based services and supports. The original November 18, 2011 seven sites were: Arizona, Georgia, Illinois, Maine, New Hampshire, and Ohio (2 sites). Added March 14 were 24 sites: Arizona, Arkansas, California, Colorado, Connecticut, Illinois, Massachusetts (2 sites), Michigan (3 sites), Nebraska, New York (4 sites), Ohio, Pennsylvania (3 sites), Texas (2 sites), and Washington (2 sites).


- Five states were interviewed by the Center for Health Care Strategies regarding managed LTSS for Medicaid-Medicare eligibles. The states were Arizona, Hawaii, Tennessee, Texas, and Wisconsin. National Council on Aging, NCOA Friday Morning Collaborative webinar, “Managed Long Term Services and Supports: An Overview of Key Issues and Guiding Principles.” Sarah Barth, Center for Health Care Strategies. April 13, 2012.

- See the “Policy and Advocacy Recommendations” section for a complete list of 10 Center for Health Care Strategies mileposts for managed LTSS. April 13, 2012. One of the 10 was to include attendant care and/or paid family caregivers. Arizona was cited as an example.

- See the “Policy and Advocacy Recommendations” section for a complete list of 10 Center for Health Care Strategies mileposts for managed LTSS. April 13, 2012. One of the 10 was to ensure program design addresses varied needs of beneficiaries. Arizona was cited as an example.

- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for support of family caregivers, in order from 1st to 5th were Oregon, Washington, Arizona, Minnesota, and Iowa. The bottom five states for support of family caregivers, in order from 51st to 46th were Oklahoma, Alabama, West Virginia, New York, and Montana.


- Thorpe, Jane Hyatt and Katherine Jett Hayes. “A New State Plan Option To Integrate Care and Financing for People Dually Eligible for Medicare and Medicaid.” George Washington University, School of Public Health and Health Services, Department of Health Policy commissioned report by the Association for Community Affiliated Plans (www.communityplans.net) – December 8, 2011. Five state duals demos were summarized by the report – Arizona, Massachusetts, Minnesota, New York, and Wisconsin were summarized. In Arizona, four Medicaid managed care contractors operate special needs plans (SNPs).

- Arizona, Michigan, California, New Hampshire, and Vermont were rated by United Cerebral Palsy as the best Medicaid programs in the nation for serving people with intellectual and other developmental disabilities. Mississippi, Illinois, Arkansas, and Texas were rated the lowest states. United Cerebral Palsy. The Case for Inclusion, 2012. May 2012.

- Mathematica analyzed state programs and special needs plans pre-CMS dual demos in Arizona, Maryland, Massachusetts, Minnesota, New Mexico, North Carolina, Oklahoma, Vermont, and Virginia. Five findings were: Strong state political and organizational leadership
and commitment over time; building enrollment is a major problem; most potential short-time savings accrue to Medicare, rather than Medicaid; program structures vary but the core elements of care coordination and multidisciplinary teams are similar; and programs are hindered by conflicting Medicare and Medicaid rules. Mathematica Policy Research. “Managing the Care of Dual Eligible Beneficiaries: A Review of Selected State Programs and Special Needs Plans.” June 2011.

■ In 2010, AARP examined four integrated care programs for people Medicaid-Medicare eligible – Mercy Care Plan and SCAN Long Term Care in Arizona and Commonwealth Care Alliance and Senior Whole Health in Massachusetts. All four programs had five common key components – supportive services, primary care enhancements, medical management of clinical services, behavioral health services, and “member services” (responsive to individual beneficiary requests. AARP Public Policy Institute. “Care Management Practices in Integrated Care Models for Dual Eligibles.” October 2010.

Arkansas

■ On March 14, CMS (Centers for Medicare and Medicaid) announced 23 additional Community based Care Transitions Program (CCTP) sites. CCTP targets Medicare patients with risk of hospital readmissions. CCTP are community based organization-acute care hospital partnerships focused on providing community based services and supports. The original November 18, 2011 seven sites were: Arizona, Georgia, Illinois, Maine, New Hampshire, and Ohio (2 sites). Added March 14 were 24 sites: Arizona, Arkansas, California, Colorado, Connecticut, Illinois, Massachusetts (2 sites), Michigan (3 sites), Nebraska, New York (4 sites), Ohio, Pennsylvania (3 sites), Texas (2 sites), and Washington (2 sites).

■ Centers for Medicare and Medicaid Services. Community Based Care Transition Program. Webinar Notes, March 27, 2012. Six States with Program Sites featured: Central Arkansas Care Transitions Program; Elder Services of Berkshire County, Massachusetts; UniNet Healthcare Network, eastern Nebraska; Brooklyn Care Transition Coalition of New York; North Philadelphia Safety Net Partnership, Pennsylvania; and Western Pennsylvania Community Care Transitions Program.


■ “Cash and Counseling” or “Independent Choices” programs - initiatives to fulfill “participant-directed,” “consumer-directed,” and “self-directed” approaches. Independent Choices allow the individual enrollee to hire and fire their personal attendants and aides (referred to as employer-authority) or manage monetary allowances on personal assistants or necessary goods and services (such as assistive technologies, transportation, home modifications) (referred to as budget authority). Enrollees may also choose agency delivered services. As of November 2011, there were 298 Participant-Directed Services programs in the U.S., with at least one program in every state. Total enrollment was 810,000 people with 59% of participants in California. The Affordable Care Act (ACA) expends this model through the “Community First-Choice” authority. Arkansas was the first program in the nation, followed by Florida and New Jersey. [Arkansas Department of Human Services; Doty, et al; National Resource Center for Participant-Directed Services.]


Managed Care, Mental Health Services, and Pharmacy Benefits: An Advocates Tool Kit. September 27, 2011. The tool kit examined state implementation in Arkansas, Massachusetts, and New York.

- Arizona, Michigan, California, New Hampshire, and Vermont were rated by United Cerebral Palsy as the best Medicaid programs in the nation for serving people with intellectual and other developmental disabilities. Mississippi, Illinois, Arkansas, and Texas were rated the lowest states. United Cerebral Palsy. The Case for Inclusion, 2012. May 2012.

- Centers for Medicare and Medicaid Services. Center for Medicare and Medicaid Innovation. Comprehensive Primary Care Initiative: Memorandums of Understanding. June 6, 2012. This is a multi-payer initiative fostering collaboration between public and private health care payers to strengthen primary care, Selected markets are in Arkansas, Colorado, Kentucky, New Jersey, New York, Ohio, Oklahoma, and Oregon.

California


- NCOA Friday Morning Collaborative webinar, State Advocate Experiences and Engagement in Duals Integration. Speakers were Bill Henning, Boston Center for Independent Living; Dennis Heaphy, Disability Policy Consortium, Massachusetts; Laurel Mildred, California Foundation for Independent Living Centers; Deborah Doctor, Disability Rights, California; and Karen Kessler, California Association of Public Authorities. March 9, 2012.

- Contra Costa Times article – California Department of Managed Health Care orders Kaiser Foundation Health Plan to stop denying PT, OT, and Speech Therapy to disabled people without an obvious physical condition. February 28, 2012

- On March 14, CMS (Centers for Medicare and Medicaid) announced 23 additional Community based Care Transitions Program (CCTP) sites. CCTP targets Medicare patients with risk of hospital readmissions. CCTP are community based organization-acute care hospital partnerships focused on providing community based services and supports. The original November 18, 2011 seven sites were: Arizona, Georgia, Illinois, Maine, New Hampshire, and Ohio (2 sites). Added March 14 were 24 sites: Arizona, Arkansas, California, Colorado, Connecticut, Illinois, Massachusetts (2 sites), Michigan (3 sites), Nebraska, New York (4 sites), Ohio, Pennsylvania (3 sites), Texas (2 sites), and Washington (2 sites).

- The Medicaid and CHIP Payment and Access Commission – “Several states have started designing strategies for measuring quality of care specifically for Medicaid enrollees with disabilities and other high-need, high-cost populations.” California is considering a dashboard of 13 adult measures for Medicaid managed care plans. Missouri amended its state plan for health homes to include behavioral health quality measures. Michigan is considering disability quality measures in its duals demonstration. Wisconsin is using “personal experience outcomes” from consumers. [The Medicaid and CHIP Payment and Access Commission, Report to the Congress on Medicaid and CHIP, March 2012. Pages 65-67]


- Federally Qualified Health Centers (FQHCs) in San Francisco and Alameda County provide home health visits, operate satellite clinics, and partner with mobile mental health teams in Permanent Supportive Housing. The San Francisco housing is Conard House and the Alameda


- “Cash and Counseling” or “Independent Choices” programs - initiatives to fulfill “participant-directed,” “consumer-directed,” and “self-directed” approaches. Independent Choices allow the individual enrollee to hire and fire their personal attendants and aides (referred to as employer-authority) or manage monetary allowances on personal assistants or necessary goods and services (such as assistive technologies, transportation, home modifications) (referred to as budget authority). Enrollees may also choose agency delivered services. As of November 2011, there were 298 Participant-Directed Services programs in the U.S., with at least one program in every state. Total enrollment was 810,000 people with 59% of participants in California. The Affordable Care Act (ACA) expends this model through the “Community First-Choice” authority. Arkansas was the first program in the nation, followed by Florida and New Jersey. [Arkansas Department of Human Services; Doty, et al; National Resource Center for Participant-Directed Services.]


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- Money Follows the Person Program Moving at “Glacial Pace” On May 24, Kaiser Health News summarized a report by Mathematica Policy Research that the CMS (Centers for Medicare and Medicaid) Medicaid state option program, Money Follows the Person, has been slow to fully implement. Money Follows the Person supports people who have transitioned back to the community from a variety of institutions. Major reasons for slow delivery are the lack of affordable and accessible housing, lack of community based work force, and not enough life-skills training. Texas has made good progress and California has been very slow because of fragmented and inadequate infrastructure. Nationwide, 14% of the elderly and 10% of people with physical disabilities returned to the institution within a year. The essence of the challenge – states need the CMS dollars to make the investment in the infrastructure; states don’t get the extra federal dollars until people are moved to the community; states can’t move people until they have the infrastructure. Kaiser Health News. “States Struggling To Meet Community Living Goals.” [Money Follows the Person – review of Mathematica Policy Research] May 25, 2012.

- The July 2, 2012 Los Angeles Times reported that “California Patients Struggle To Transition to Managed Care System,” reporting that people with disabilities sometimes have to change their doctor, have treatment delayed, and have to travel long distances to see specialists.

Colorado


- On March 14, CMS (Centers for Medicare and Medicaid) announced 23 additional Community Based Transitions Program (CCTP) sites. CCTP targets Medicare patients with risk of hospital readmissions. CCTP are community based organization-acute care hospital partnerships focused on providing community based services and supports. The original November 18, 2011 seven sites were: Arizona, Georgia, Illinois,
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Connecticut


- On March 14, CMS (Centers for Medicare and Medicaid) announced 23 additional Community Based Care Transitions Program (CCTP) sites. CCTP targets Medicare patients with risk of hospital readmissions. CCTP are community based organization-acute care hospital partnerships focused on providing community based services and supports. The original November 18, 2011 seven sites were: Arizona, Georgia, Illinois, Maine, New Hampshire, and Ohio (2 sites). Added March 14 were 24 sites: Arizona, Arkansas, California, Colorado, Connecticut, Illinois, Massachusetts (2 sites), Michigan (3 sites), Nebraska, New York (4 sites), Ohio, Pennsylvania (3 sites), Texas (2 sites), and Washington (2 sites).


- University of Massachusetts, Institute for Community Inclusion. “State Data: The National Report on Employment Services and Outcomes.” Winter 2011. Connecticut, Louisiana, New Hampshire, Oklahoma, and Washington all reported that more than 40% of individuals receiving day and employment services were receiving integrated employment services. (page 9)

- United Cerebral Palsy. The Case for Inclusion, 2012. May 2012. States are rated on “four key aspects of a high functioning Medicaid program” – (1) participation in their communities, (2) have satisfying lives and valued social roles, (3) have sufficient access to needed support and control over that support to contribute to the lifestyles they desire, and (4) live in safe and healthy environments. Only 15 states supported a large share of families through family supports. More than a quarter of a million people (268,000 nationwide) are on waiting lists for home and community based services. Just nine states have at least one third (33%) of individuals with ID/DD working in competitive employment. These states are Alaska, Connecticut, Delaware, Maryland, Michigan, Oklahoma, Pennsylvania, Vermont, and Washington.

Delaware

- Six states plan on implementing Medicaid managed LTSS programs in 2012. The six states are California, Delaware, Indiana, Nevada, New Jersey, and Rhode Island. National Association of States United for Aging and Disabilities-Health Management Associates-AARP Public


- Primary Care Home Visits Demo Sites Announced: On April 26, 2012 CMS (Centers for Medicare and Medicaid Services) announced the selection of 16 organizations to provide primary care in the home setting to improve care for people with multiple chronic conditions. The 16 sites are in Delaware, Florida (2), Georgia, Kentucky, Massachusetts, Michigan (2), North Carolina, New York (2), Ohio, Oregon, Texas (2), and Wisconsin.


- United Cerebral Palsy. The Case for Inclusion, 2012. May 2012. States are rated on “four key aspects of a high functioning Medicaid program” — (1) participation in their communities, (2) have satisfying lives and valued social roles, (3) have sufficient access to needed support and control over that support to contribute to the lifestyles they desire, and (4) live in safe and healthy environments. Only 15 states supported a large share of families through family supports. More than a quarter of a million people (268,000 nationwide) are on waiting lists for home and community based services. Just nine states have at least one third (33%) of individuals with ID/DD working in competitive employment. These states are Alaska, Connecticut, Delaware, Maryland, Michigan, Oklahoma, Pennsylvania, Vermont, and Washington.

District of Columbia


- National Association of State Directors of Developmental Disabilities Services (NASDDS)-Human Services Research Institute (HSRI) National Core Indicators (NCI) Program. 2009-2010

- States with the highest proportion of people having a job in the community were DC, Georgia, Maine, Oklahoma, and Wyoming. However, only 52% of the people’s hourly earnings were at or above the state’s minimum wage.

Florida

- APA (American Psychiatric Assn)-MHLG petition drive – “Don’t Let BC/BS of Florida Discriminate Against Mental Health Patients.” National mental health associations have launched a petition to federal and state officials objecting to a Blue Cross-Blue Shield of Florida managed care tactic. In late 2011, BC/BS FL terminated contracts with all behavioral health providers in the state. BC/BS contracted with New Directions Behavioral Health which required much more restrictive provider contracts. March 10, 2012


- “Cash and Counseling” or “Independent Choices” programs - initiatives to fulfill “participant-directed,” “consumer-directed,” and “self-directed” approaches. Independent Choices allow the individual enrollee to hire and fire their personal attendants and aides (referred
to as employer-authority) or manage monetary allowances on personal assistants or necessary goods and services (such as assistive technologies, transportation, home modifications) (referred to as budget authority). Enrollees may also choose agency delivered services. As of November 2011, there were 298 Participant-Directed Services programs in the U.S., with at least one program in every state. Total enrollment was 810,000 people with 59% of participants in California. The Affordable Care Act (ACA) expends this model through the “Community First-Choice” authority. Arkansas was the first program in the nation, followed by Florida and New Jersey. [Arkansas Department of Human Services; Doty, et al; National Resource Center for Participant-Directed Services.]

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Georgia

On March 14, CMS (Centers for Medicare and Medicaid) announced 23 additional Community Based Care Transitions Program (CCTP) sites. CCTP targets Medicare patients with risk of hospital readmissions. CCTP are community based organization-acute care hospital partnerships focused on providing community based services and supports. The original November 18, 2011 seven sites were: Arizona, Georgia, Illinois, Maine, New Hampshire, and Ohio (2 sites). Added March 14 were 24 sites: Arizona, Arkansas, California, Colorado, Connecticut, Illinois, Massachusetts (2 sites), Michigan (3 sites), Nebraska, New York (4 sites), Ohio, Pennsylvania (3 sites), Texas (2 sites), and Washington (2 sites).

SAMHSA. Peer Respite Services: Transforming Crisis to Wellness. August 4, 2011 training webinar. Featured were Georgia – Mental Health Consumer Network; New Jersey – Institute for Wellness and Recovery Initiatives; and New York – Projects to Empower and Organize the Psychiatrically Labeled – Hospital Diversion Services.

Gold, Steve alert – “Comparing States on Access to Community Based Services.” Info Bulletin #354, March 30, 2012. One of four criteria is participants receiving HCBS per 1,000 population. National average is 9.34. Georgia is the lowest at 3.22.

Primary Care Home Visits Demo Sites Announced: On April 26, 2012 CMS (Centers for Medicare and Medicaid Services) announced the selection of 16 organizations to provide primary care in the home setting to improve care for people with multiple chronic conditions. The 16 sites are in Delaware, Florida (2), Georgia, Kentucky, Massachusetts, Michigan (2), North Carolina, New York (2), Ohio, Oregon, Texas (2), and Wisconsin.


AARP Public Policy Institute. State Long Term Services and Supports Scorecard – What Distinguishes High from Low Ranking States – Overview of Three Cases. May 8, 2012. Minnesota ranked number one in the nation; Idaho ranked #19; and Georgia ranked #42. Minnesota is the only state to achieve a first quartile rank across all four dimensions examined. Idaho’s biggest challenge is the dimension of affordability and access. Minnesota and Idaho have supported and invested in HCBS. Georgia devotes a significant majority of its Medicaid dollars in institutional care. Idaho has no waiting list; Georgia has more than 7,500 people on its Medicaid HCBS waiver waiting list. Minnesota uses its Managed Care system to provide clear financial incentives to favor HCBS over institutional settings. Regarding single points of entry through Aging and Disability Resource Centers, Minnesota ranks 1st in the...
nation, Idaho ranks last, and Georgia ranks 24th. Minnesota state agencies are integrated, while Georgia and Idaho have fragmented systems with no clear locus of LTSS responsibility. Minnesota is ranked 3rd in the nation and Idaho is ranked 6th in the nation for life satisfaction expressed by family caregivers; Georgia ranks 47th.

- National Association of State Directors of Developmental Disabilities Services (NASDDS)-Human Services Research Institute (HSRI) National Core Indicators (NCI) Program. 2009-2010

- States with the highest proportion of people having a job in the community were DC, Georgia, Maine, Oklahoma, and Wyoming. However, only 52% of the people’s hourly earnings were at or above the state’s minimum wage.

- Centers for Medicare and Medicaid Services. Georgia-Iowa-Mississippi-Missouri join Maryland and New Hampshire as CMS Balancing Incentives Grantees. There are now six states receiving Centers for Medicare and Medicaid (CMS) grants under the Affordable Care Act to rebalance their systems toward home and community based services. June 20, 2012.

Guam

Hawaii


- Five states were interviewed by the Center for Health Care Strategies regarding managed LTSS for Medicaid-Medicare eligibles. The states were Arizona, Hawaii, Tennessee, Texas, and Wisconsin. National Council on Aging. NCOA Friday Morning Collaborative webinar, “Managed Long Term Services and Supports: An Overview of Key Issues and Guiding Principles.” Sarah Barth, Center for Health Care Strategies. April 13, 2012.

- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states, in order from 1st to 5th were Minnesota, Washington, Oregon, Hawaii, and Wisconsin. The bottom five states, in order from 51st to 46th were Mississippi, Alabama, West Virginia, Oklahoma, and Indiana.

- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for quality of life and quality of care, in order from 1st to 5th were Alaska, North Dakota, Hawaii, Minnesota, and Iowa. The bottom five states for quality of life and quality of care, in order from 51st to 46th were Mississippi, Kentucky, Oklahoma, Tennessee, and Maine.


Idaho

by AARP Public Policy Institute. State Long Term Services and Supports Scorecard – What Distinguishes High from Low Ranking States – Overview of Three Cases. May 8, 2012. Minnesota ranked number one in the nation; Idaho ranked #19; and Georgia ranked #42. Minnesota is the only state to achieve a first quartile rank across all four dimensions examined. Idaho’s biggest challenge is the dimension of affordability and access. Minnesota and Idaho have supported and invested in HCBS. Georgia devotes a significant majority of its Medicaid dollars in institutional care. Idaho has no waiting list; Georgia has more than 7,500 people on its Medicaid HCBS waiver waiting list. Minnesota uses its Managed Care system to provide clear financial incentives to favor HCBS over institutional settings. Regarding single points of entry through Aging and Disability Resource Centers, Minnesota ranks 1st in the nation, Idaho ranks last, and Georgia ranks 24th. Minnesota state agencies are integrated, while Georgia and Idaho have fragmented systems with no clear locus of LTSS responsibility. Minnesota is ranked 3rd in the nation and Idaho is ranked 6th in the nation for life satisfaction expressed by family caregivers; Georgia ranks 47th.

Illinois


- On March 14, CMS (Centers for Medicare and Medicaid) announced 23 additional Community Based Care Transitions Program (CCTP) sites. CCTP targets Medicare patients with risk of hospital readmissions. CCTP are community based organization-acute care hospital partnerships focused on providing community based services and supports. The original November 18, 2011 seven sites were: Arizona, Georgia, Illinois, Maine, New Hampshire, and Ohio (2 sites). Added March 14 were 24 sites: Arizona, Arkansas, California, Colorado, Connecticut, Illinois, Massachusetts (2 sites), Michigan (3 sites), Nebraska, New York (4 sites), Ohio, Pennsylvania (3 sites), Texas (2 sites), and Washington (2 sites).

- Gold, Steve alert – “Comparing States on Access to Community Based Services.” Info Bulletin #354, March 30, 2012. One of the four criteria is % of HCBS to total Medicaid long term care expenditures. The national average is 45%. Three states – IL, MS, ND – have the lowest at 30%.


- Two community mental health centers (CMHCs) (Tresholds and Trilogy) in Chicago provide mental health services to clients residing in both scattered-site housing and Permanent Supportive Housing. However, mental health services are not integrated with primary health services. U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Medicaid Financing for Services in Supportive Housing for Chronically Homeless People: Current Practices and Opportunities. February 2012 pages 20-21.


Medicaid health homes, duals demo, and partnership for patients initiative.

- U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Federal Financing of Supported Employment and Customized Employment for People with Mental Illnesses: Final Report. February 2011. Four states were analyzed for their recent success and experience with implementing supported employment (SE) programs, partially financed with Medicaid. The states were Illinois, Kansas, Maryland, and Washington. The rehabilitation and targeted case management Medicaid options and the Section 1915 HCBS options finance individual supports that are partially related to employment goals. Maryland also authorizes Medicaid “buy-in” for people with disabilities who work.


- HHS ASPE report – Illinois Medicaid definition of medical necessity for people with serious mental illness - SERVICE INITIATION CRITERIA (must meet all of the following):

  1. The individual has indicated their agreement with the need for and choice of this service modality and has been actively involved in the development and implementation of the treatment plan.

  2. The individual’s severity/complexity of symptoms and level of functional impairment require this service, as evidenced by:

     a. The individual presents minimal risk of danger to self or others;

     b. The individual has significantly impaired role functioning and skill deficits that adversely affect **at least two of the following areas** and that can be expected to improve through intensive, curriculum-based, short-term skills training in a facility setting:

        i. management of financial affairs

        ii. ability to procure needed public services or other community support services

        iii. socialization, communication, adaptation, problem solving, and coping

        iv. activities of daily living, including personal care; meal preparation; maintaining housing; accessing social, vocational, and recreational opportunities in the community; and establishing or modifying habits and routines

        v. self-management of symptoms or recovery

        vi. concentration, endurance, attention, direction following, and planning and organization skills necessary to progress in recovery

     c. The nature of the individual’s impairment and/or skill deficits can be effectively remediated through focused skills-training activities that prepare the individual to apply new skills in their personal living environments (e.g., home, neighborhood, school, and work) and relationships (e.g., roommates, family, friends, neighbors, landlords, and co-workers).

     d. The individual’s current assessment identifies the specific skill deficits that will be addressed through focused skills-training.

     e. Individual has a composite Level of Care Utilization System (LOCUS) score equating to Level of Care 3 or higher. [These are only a tiny component of the complete policy.]

- Arizona, Michigan, California, New Hampshire, and Vermont were rated by United Cerebral Palsy as the best Medicaid programs in the nation for serving people with intellectual and other developmental disabilities. Mississippi, Illinois, Arkansas, and Texas were rated the lowest states. United Cerebral Palsy. The Case for Inclusion, 2012. May 2012.

**Indiana**

- Gold, Steve alert – “Comparing States on Access to Community Based Services.” Info Bulletin #354, March 30, 2012. One of the four criteria is percent of HCBS to total Medicaid long term care participants. The national average is 62%. The lowest in the nation is Indiana at 34%.


AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states, in order from 1st to 5th were Minnesota, Washington, Oregon, Hawaii, and Wisconsin. The bottom five states, in order from 51st to 46th were Mississippi, Alabama, West Virginia, Oklahoma, and Indiana.

The American Hospital Association has proposed 12 core elements for successful care management of vulnerable seniors, including Medicaid-Medicare eligible. These are hospital based programs focused on seniors with chronic illness. The 12 core elements are (1) complete comprehensive assessment and reassessment, (2) periodic visits, (3) protocol-based planning, (4) person-centered care principles and planning, (5) team-based management centered on primary care, (6) data sharing and integrated information systems, (7) alignment of financial incentives, (8) networks and community partnerships, (9) non-health care services provided (such as transportation), (10) home-based services, (11) center-based “day care,” and (12) cultural competency and equity standards. The AHA identified 10 hospital based “promising models.” One the 10 is the Geriatric Resources program at Wishard Health Systems, Indianapolis. Wishard Geriatric Resources delivers all 12 elements except items #9 and #11 – non-health services provided and “day care.”


Iowa

National Academy of State Health Policy and Health Resources and Services Administration. Six State Teams for Medicaid-Safety Net Learning Collaborative Selected. April 10, 2012. The states were Alaska, Iowa, Maryland, Maine, Minnesota, and Texas.

AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for quality of life and quality of care, in order from 1st to 5th were Alaska, North Dakota, Hawaii, Minnesota, and Iowa. The bottom five states for quality of life and quality of care, in order from 51st to 46th were Mississippi, Kentucky, Oklahoma, Tennessee, and Maine.

AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for support of family caregivers, in order from 1st to 5th were Oregon, Washington, Arizona, Minnesota, and Iowa. The bottom five states for support of family caregivers, in order from 51st to 46th were Oklahoma, Alabama, West Virginia, New York, and Montana.


Centers for Medicare and Medicaid Services. Georgia-Iowa-Mississippi-Missouri join Maryland and New Hampshire as CMS Balancing
Incentives Grantees. There are now six states receiving Centers for Medicare and Medicaid (CMS) grants under the Affordable Care Act to rebalance their systems toward home and community based services. June 20, 2012.

Kansas

- U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Federal Financing of Supported Employment and Customized Employment for People with Mental Illnesses: Final Report. February 2011. Four states were analyzed for their recent success and experience with implementing supported employment (SE) programs, partially financed with Medicaid. The states were Illinois, Kansas, Maryland, and Washington. The rehabilitation and targeted case management Medicaid options and the Section 1915 HCBS options finance individual supports that are partially related to employment goals. Maryland also authorizes Medicaid “buy-in” for people with disabilities who work.
- RESNA – Nell Bailey May 24, 2012 memo to Clarke Ross – Assistive Technology and State Medicaid programs. Many of the state AT programs refurbish used equipment (AT, DME, and computers) and make them available to individuals with disabilities that can’t afford the technology otherwise. In a couple of states (Kansas and Vermont), they are working with state Medicaid to provide reused equipment. Kansas: ATK provides quality used devices through two efforts. KEE is a reuse partnership between Kansas Health Policy Authority and ATK. Through KEE, eligible Kansans can get quality, refurbished durable medical equipment such as manual and power wheelchairs, patient lifts, electronic hospital beds, shower chairs, communication devices, and other health devices. For Vermont, go to http://atp.vermont.gov/get-at-stuff and scroll down to the bottom of the page to see what they are doing and what’s covered.

Kentucky

- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for quality of life and quality of care, in order from 1st to 5th were Alaska, North Dakota, Hawaii, Minnesota, and Iowa. The bottom five states for quality of life and quality of care, in order from 51st to 46th were Mississippi, Kentucky, Oklahoma, Tennessee, and Maine.
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Centers for Medicare and Medicaid Services. Center for Medicare and Medicaid Innovation. Comprehensive Primary Care Initiative: Memorandums of Understanding. June 6, 2012. This is a multi-payer initiative fostering collaboration between public and private health care payers to strengthen primary care, Selected markets are in Arkansas, Colorado, Kentucky, New Jersey, New York, Ohio, Oklahoma, and Oregon.

**Louisiana**

- Louisiana submitted December 2011 and CMS approved January 2012 a HCBS waiver to provide services to people with mental illness, addiction disorders, or co-occurring disorders to those receiving housing assistance. The mental health services are delivered by ACT (Assertive Community Treatment) teams. U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Medicaid Financing for Services in Supportive Housing for Chronically Homeless People: Current Practices and Opportunities. February 2012. Pages 36 and 38.
- University of Massachusetts, Institute for Community Inclusion. “State Data: The National Report on Employment Services and Outcomes.” Winter 2011. Connecticut, Louisiana, New Hampshire, Oklahoma, and Washington all reported that more than 40% of individuals receiving day and employment services were receiving integrated employment services. (page 9).

**Maine**

- On March 14, CMS (Centers for Medicare and Medicaid) announced 23 additional Community Based Care Transitions Program (CCTP) sites. CCTP targets Medicare patients with risk of hospital readmissions. CCTP are community based organization-acute care hospital partnerships focused on providing community based services and supports. The original November 18, 2011 seven sites were: Arizona, Georgia, Illinois, Maine, New Hampshire, and Ohio (2 sites). Added March 14 were 24 sites: Arizona, Arkansas, California, Colorado, Connecticut, Illinois, Massachusetts (2 sites), Michigan (3 sites), Nebraska, New York (4 sites), Ohio, Pennsylvania (3 sites), Texas (2 sites), and Washington (2 sites).
- National Academy of State Health Policy and Health Resources and Services Administration. Six State Teams for Medicaid-Safety Net Learning Collaborative Selected. April 10, 2012. The states were Alaska, Iowa, Maryland, Maine, Minnesota, and Texas.
- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for quality of life and quality of care, in order from 1st to 5th were Alaska, North Dakota, Hawaii, Minnesota, and Iowa. The bottom five states for quality of life and quality of care, in order from 51st to 46th were Mississippi, Kentucky, Oklahoma, Tennessee, and Maine.
States with the highest proportion of people having a job in the community were DC, Georgia, Maine, Oklahoma, and Wyoming. However, only 52% of the people’s hourly earnings were at or above the state’s minimum wage.

Maryland


- National Academy of State Health Policy and Health Resources and Services Administration. Six State Teams for Medicaid-Safety Net Learning Collaborative Selected. April 10, 2012. The states were Alaska, Iowa, Maryland, Maine, Minnesota, and Texas.

- The American Hospital Association has proposed 12 core elements for successful care management of vulnerable seniors, including Medicaid-Medicare eligible. These are hospital based programs focused on seniors with chronic illness. The 12 core elements are (1) complete comprehensive assessment and reassessment, (2) periodic visits, (3) protocol-based planning, (4) person-centered care principles and planning, (5) team-based management centered on primary care, (6) data sharing and integrated information systems, (7) alignment of financial incentives, (8) networks and community partnerships, (9) non-health care services provided (such as transportation), (10) home based services, (11) center-based “day care,” and (12) cultural competency and equity standards. The AHA identified 10 hospital based “promising models.” One of the 10 is the Elder Plus program at Johns Hopkins Health System, Baltimore. Hopkins Elder Plus delivers all 12 elements except item #6 – data sharing and integrated information systems. Another of the 10 programs is the Geriatric Emergency program at Holy Cross Hospital, Silver Spring, Maryland. However, Holy Cross only provides 4 of the 12 core elements – 1, 3, 4, and 5.


- U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Federal Financing of Supported Employment and Customized Employment for People with Mental Illnesses: Final Report. February 2011. Four states were analyzed for their recent success and experience with implementing supported employment (SE) programs, partially financed with Medicaid. The states were Illinois, Kansas, Maryland, and Washington. The rehabilitation and targeted case management Medicaid options and the Section 1915 HCBS options finance individual supports that are partially related to employment goals. Maryland also authorizes Medicaid “buy-in” for people with disabilities who work.

- United Cerebral Palsy. The Case for Inclusion, 2012. May 2012. States are rated on “four key aspects of a high functioning Medicaid program” – (1) participation in their communities, (2) have satisfying lives and valued social roles, (3) have sufficient access to needed support and control over that support to contribute to the lifestyles they desire, and (4) live in safe and healthy environments. Only 15 states supported a large share of families through family supports. More than a quarter of a million people (268,000 nationwide) are on waiting lists for home and community based services. Just nine states have at least one third (33%) of individuals with ID/DD working in competitive employment. These states are Alaska, Connecticut, Delaware, Maryland, Michigan, Oklahoma, Pennsylvania, Vermont, and Washington.

Mathematica analyzed state programs and special needs plans pre-CMS dual demos in Arizona, Maryland, Massachusetts, Minnesota, New Mexico, North Carolina, Oklahoma, Vermont, and Virginia. Five findings were: Strong state political and organizational leadership and commitment over time; building enrollment is a major problem; most potential short-time savings accrue to Medicare, rather than Medicaid; program structures vary but the core elements of care coordination and multidisciplinary teams are similar; and programs are hindered by conflicting Medicare and Medicaid rules. Mathematica Policy Research. “Managing the Care of Dual Eligible Beneficiaries: A Review of Selected State Programs and Special Needs Plans.” June 2011.

Centers for Medicare and Medicaid Services. Georgia-Iowa-Mississippi-Missouri Join Maryland and New Hampshire as CMS Balancing Incentives Grantees. There are now six states receiving Centers for Medicare and Medicaid (CMS) grants under the Affordable Care Act to rebalance their systems toward home and community based services. June 20, 2012.

Massachusetts


Medicaid-Medicare eligible Beneficiaries – Centers for Medicare and Medicaid Services – State proposals publicly available: Illinois, Massachusetts, Michigan, Minnesota, New York, North Carolina, Ohio, Oklahoma, Oregon, Vermont, Washington, Wisconsin

NCOA Friday Morning Collaborative webinar, State Advocate Experiences and Engagement in Duals Integration. Speakers were Bill Henning, Boston Center for Independent Living; Dennis Heaphy, Disability Policy Consortium, Massachusetts; Laurel Mildred, California Foundation for Independent Living Centers; Deborah Doctor, Disability Rights, California; and Karen Kessler, California Association of Public Authorities. March 9, 2012.

On March 14, CMS (Centers for Medicare and Medicaid) announced 23 additional Community Based Care Transitions Program (CCTP) sites. CCTP targets Medicare patients with risk of hospital readmissions. CCTP are community based organization-acute care hospital partnerships focused on providing community based services and supports. The original November 18, 2011 seven sites were: Arizona, Georgia, Illinois, Maine, New Hampshire, and Ohio (2 sites). Added March 14 were 24 sites: Arizona, Arkansas, California, Colorado, Connecticut, Illinois, Massachusetts (2 sites), Michigan (3 sites), Nebraska, New York (4 sites), Ohio, Pennsylvania (3 sites), Texas (2 sites), and Washington (2 sites).

Centers for Medicare and Medicaid Services. Community Based Care Transition Program. Webinar Notes, March 27, 2012. Six States with Program Sites featured: Central Arkansas Care Transitions Program; Elder Services of Berkshire County, Massachusetts; UniNet Healthcare Network, eastern Nebraska; Brooklyn Care Transition Coalition of New York; North Philadelphia Safety Net Partnership, Pennsylvania; and Western Pennsylvania Community Care Transitions Program.


Under the managed behavioral health carve-out program, Massachusetts (MBHP) has flexibility to identify special need population cohorts and create special contracts with providers to cover these special needs. MBHP collaborates with the Massachusetts Housing and Shelter Alliance (CSPECH) providing home care services, case management, and medical and behavioral health services to 24 people receiving HUD Housing Choice Vouchers. U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Medicaid Financing for Services in Supportive Housing for Chronically Homeless People: Current Practices and Opportunities. February 2012. Page 45.

The American Hospital Association has proposed 12 core elements for successful care management of vulnerable seniors, including Medicaid-Medicare eligible. These are hospital based programs focused on seniors with chronic illness. The 12 core elements are (1) complete comprehensive assessment and reassessment, (2) periodic visits, (3) protocol-based planning, (4) person-centered care principles and planning, (5) team-based management centered on primary care, (6) data sharing and integrated information systems, (7) alignment of financial incentives, (8) networks and community partnerships, (9) non-health care services provided (such as transportation), (10) home based services, (11) center-based “day care,” and (12) cultural competency and equity standards. The AHA identified 10 hospital based “promising models.” One of the 10 is the Senior Care Options Program at Commonwealth Care Alliance, Massachusetts. Commonwealth delivers all 12 elements except items #11 and #12 - “day care” and “cultural competence.”

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Agency for Healthcare Research and Quality. “Coordinating Care for Adults with Complex Care Needs in the Patient-Centered Medical Home: Challenges and Solutions.” Prepared by Mathematica Policy Research. January 2012. Five PCMHs were selected for review: Commonwealth Care Alliance, Massachusetts; Minnesota Health Care Homes (state Medicaid program); Community Care of North Carolina; Summa Health System, Ohio; and Community Health Partnership in Wisconsin.


As part of its Medicaid mental health managed care initiatives, Massachusetts and Philadelphia, Pennsylvania financed third party, independent, consumer and family directed consumer satisfaction monitoring teams. The teams focus on documented dis-satisfaction and regularly meet with health plans to resolve areas of dis-satisfaction. [NAMI and Ross]

Thorpe, Jane Hyatt and Katherine Jett Hayes. “A New State Plan Option To Integrate Care and Financing for People Dually Eligible for Medicare and Medicaid.” George Washington University, School of Public Health and Health Services, Department of Health Policy commissioned report by the Association for Community Affiliated Plans (www.communityplans.net) – December 8, 2011. Five state duals demos were outlined by the report – Arizona, Massachusetts, Minnesota, New York, and Wisconsin were summarized.


NAMI. Integrating Mental Health and Pediatric Primary Care: A Family Guide. November 2011. NAMI recommends three programs that have successfully integrated mental health and pediatric primary care programs – Cherokee Health Systems, Tennessee; Massachusetts Child Psychiatry Access Project; and North Carolina Center for Excellence for Integrated Care.
Mathematica analyzed state programs and special needs plans pre-CMS dual demos in Arizona, Maryland, Massachusetts, Minnesota, New Mexico, North Carolina, Oklahoma, Vermont, and Virginia. Five findings were: Strong state political and organizational leadership and commitment over time; building enrollment is a major problem; most potential short-time savings accrue to Medicare, rather than Medicaid; program structures vary but the core elements of care coordination and multidisciplinary teams are similar; programs are hindered by conflicting Medicare and Medicaid rules. Mathematica Policy Research. “Managing the Care of Dual Eligible Beneficiaries: A Review of Selected State Programs and Special Needs Plans.” June 2011.

In 2010, AARP examined four integrated care programs for people Medicaid-Medicare eligible – Mercy Care Plan and SCAN Long Term Care in Arizona and Commonwealth Care Alliance and Senior Whole Health in Massachusetts. All four programs had five common key components – supportive services, primary care enhancements, medical management of clinical services, behavioral health services, and “member services” (responsive to individual beneficiary requests. AARP Public Policy Institute. “Care Management Practices in Integrated Care Models for Dual Eligibles.” October 2010).

Michigan


On March 14, CMS announced 23 additional Community Based Care Transitions Program (CCTP) sites. CCTP targets Medicare patients with risk of hospital readmissions. CCTP are community based organization-acute care hospital partnerships focused on providing community based services and supports. The original November 18, 2011 seven sites were: Arizona, Georgia, Illinois, Maine, New Hampshire, and Ohio (2 sites). Added March 14 were 24 sites: Arizona, Arkansas, California, Colorado, Connecticut, Illinois, Massachusetts (2 sites), Michigan (3 sites), Nebraska, New York (4 sites), Ohio, Pennsylvania (3 sites), Texas (2 sites), and Washington (2 sites).

The Medicaid and CHIP Payment and Access Commission – “Several states have started designing strategies for measuring quality of care specifically for Medicaid enrollees with disabilities and other high-need, high-cost populations.” California is considering a dashboard of 13 adult measures for Medicaid managed care plans. Missouri amended its state plan for health homes to include behavioral health quality measures. Michigan is considering disability quality measures in its duals demonstration. Wisconsin is using “personal experience outcomes” from consumers. The Medicaid and CHIP Payment and Access Commission, Report to the Congress on Medicaid and CHIP, March 2012. Pages 65-67]


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The Arc recommended national model – State of Michigan, Medicaid Policy Manual, new section 17 – “Additional Mental Health Services” - definition of medical necessity. 2.5.A. Medical Necessity Criteria: Mental health, developmental disabilities, and substance abuse services and supports, services, and treatment:

- Necessary for screening and assessing the presence of a mental illness, developmental disability, or substance use disorder; and/or
- Required to identify and evaluate a mental illness, developmental disability, or substance use disorder; and/or
- Intended to treat, ameliorate, diminish, or stabilize the symptoms of mental illness, developmental disability, or substance use disorder; and/or
- Expected to arrest or delay the progression of a mental illness, developmental disability, or substance use disorder; and/or
- Designed to assist the beneficiary to attain or maintain a sufficient level of functioning in order to achieve his goals of community inclusion and participation, independence, recovery, or productivity.

[These are only a small component of the policy.]

Arizona, Michigan, California, New Hampshire, and Vermont were rated by United Cerebral Palsy as the best Medicaid programs in the nation for serving people with intellectual and other developmental disabilities. Mississippi, Illinois, Arkansas, and Texas were rated the lowest states. United Cerebral Palsy. The Case for Inclusion, 2012. May 2012.

United Cerebral Palsy. The Case for Inclusion, 2012. May 2012. States are rated on “four key aspects of a high functioning Medicaid program” – (1) participation in their communities, (2) have satisfying lives and valued social roles, (3) have sufficient access to needed support and control over that support to contribute to the lifestyles they desire, and (4) live in safe and healthy environments. Only 15 states supported a large share of families through family supports. More than a quarter of a million people (268,000 nationwide) are on waiting lists for home and community based services. Just nine states have at least one third (33%) of individuals with ID/DD working in competitive employment. These states are Alaska, Connecticut, Delaware, Maryland, Michigan, Oklahoma, Pennsylvania, Vermont, and Washington.

Minnesota

- Academy Health Long Term Care Interest Group Policy Seminar. Speaker – Alex Bartolic, Director, Division of Disability Services, Minnesota Department of Human Services. February 15, 2012.
- National Academy of State Health Policy and Health Resources and Services Administration. Six State Teams for Medicaid-Safety Net Learning Collaborative Selected. April 10, 2012. The states were Alaska, Iowa, Maryland, Maine, Minnesota, and Texas.

AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states, in order from 1st to 5th were Minnesota, Washington, Oregon, Hawaii, and Wisconsin. The bottom five states, in order from 51st to 46th were Mississippi, Alabama, West Virginia, Oklahoma, and Indiana.

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The American Hospital Association has proposed 12 core elements for successful care management of vulnerable seniors, including Medicaid-Medicare eligible. These are hospital based programs focused on seniors with chronic illness. The 12 core elements are (1) complete comprehensive assessment and reassessment, (2) periodic visits, (3) protocol-based planning, (4) person-centered care principles and planning, (5) team-based management centered on primary care, (6) data sharing and integrated information systems, (7) alignment of financial incentives, (8) networks and community partnerships, (9) non-health care services provided (such as transportation), (10) home based services, (11) center-based “day care,” and (12) cultural competency and equity standards. The AHA identified 10 hospital based “promising models.” One of the 10 is the Comprehensive Care Management for Seniors Living in Assisted Living sites, nursing facilities, and their homes at Fairview Health Systems, Red Wing, MN. Fairview delivers all 12 elements except items #10 and #11 – home based services and “day care.”

Agency for Healthcare Research and Quality. “Coordinating Care for Adults with Complex Care Needs in the Patient-Centered Medical Home: Challenges and Solutions.” Prepared by Mathematica Policy Research. January 2012. Five PCMHs were selected for review: Commonwealth Care Alliance, Massachusetts; Minnesota Health Care Homes (state Medicaid program); Community Care of North Carolina; Summa Health System, Ohio; and Community Health Partnership in Wisconsin.


AARP Public Policy Institute. State Long Term Services and Supports Scorecard — What Distinguishes High from Low Ranking States — Overview of Three Cases. May 8, 2012. Minnesota ranked number one in the nation; Idaho ranked #19; and Georgia ranked #42. Minnesota is the only state to achieve a first quartile rank across all four dimensions examined. Idaho’s biggest challenge is the dimension of affordability and access. Minnesota and Idaho have supported and invested in HCBS. Georgia devotes a significant majority of its Medicaid dollars in institutional care. Idaho has no waiting list; Georgia has more than 7,500 people on its Medicaid HCBS waiver waiting list. Minnesota uses its Managed Care system to provide clear financial incentives to favor HCBS over institutional settings. Regarding single
points of entry through Aging and Disability Resource Centers, Minnesota ranks 1st in the nation, Idaho ranks last, and Georgia ranks 24th. Minnesota state agencies are integrated, while Georgia and Idaho have fragmented systems with no clear locus of LTSS responsibility. Minnesota is ranked 3rd in the nation and Idaho is ranked 6th in the nation for life satisfaction expressed by family caregivers; Georgia ranks 47th.

Thorpe, Jane Hyatt and Katherine Jett Hayes. “A New State Plan Option To Integrate Care and Financing for People Dually Eligible for Medicare and Medicaid.” George Washington University, School of Public Health and Health Services, Department of Health Policy commissioned report by the Association for Community Affiliated Plans (www.communityplans.net) – December 8, 2011. Five state duals demos were summarized by the report – Arizona, Massachusetts, Minnesota, New York, and Wisconsin were summarized.

Mathematica analyzed state programs and special needs plans pre-CMS dual demos in Arizona, Maryland, Massachusetts, Minnesota, New Mexico, North Carolina, Oklahoma, Vermont, and Virginia. Five findings were: Strong state political and organizational leadership and commitment over time; building enrollment is a major problem; most potential short-time savings accrue to Medicare, rather than Medicaid; program structures vary but the core elements of care coordination and multidisciplinary teams are similar; and programs are hindered by conflicting Medicare and Medicaid rules. Mathematica Policy Research. “Managing the Care of Dual Eligible Beneficiaries: A Review of Selected State Programs and Special Needs Plans.” June 2011.

**Mississippi**

- Gold, Steve alert – “Comparing States on Access to Community Based Services.” Info Bulletin #354, March 30, 2012. One of the four criteria is % of HCBS to total Medicaid long term care expenditures. The national average is 45%. Three states – IL, MS, ND – have the lowest at 30%.


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- Arizona, Michigan, California, New Hampshire, and Vermont were rated by United Cerebral Palsy as the best Medicaid programs in the nation for serving people with intellectual and other developmental disabilities. Mississippi, Illinois, Arkansas, and Texas were rated the lowest states. United Cerebral Palsy. The Case for Inclusion, 2012. May 2012.
Centers for Medicare and Medicaid Services. Georgia-Iowa-Mississippi-Missouri Join Maryland and New Hampshire as CMS Balancing Incentives Grantees. There are now six states receiving Centers for Medicare and Medicaid (CMS) grants under the Affordable Care Act to rebalance their systems toward home and community based services. June 20, 2012.

Missouri

The Medicaid and CHIP Payment and Access Commission – “Several states have started designing strategies for measuring quality of care specifically for Medicaid enrollees with disabilities and other high-need, high-cost populations.” California is considering a dashboard of 13 adult measures for Medicaid managed care plans. Missouri amended its state plan for health homes to include behavioral health quality measures. Michigan is considering disability quality measures in its duals demonstration. Wisconsin is using “personal experience outcomes” from consumers. [The Medicaid and CHIP Payment and Access Commission, Report to the Congress on Medicaid and CHIP, March 2012. Pages 65-67]

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Mental Health Weekly. Collaborative Care – Missouri Department of Mental Health Chronic Care Improvement Program and Health Care Homes. Featured program at National Council for Community Behavioral Health annual conference. April 23, 2012. Features program at May 4 Alliance for Health Reform briefing on Primary Care-Behavioral Health Integration.

The Crider Health Center in Missouri started as a psychosocial rehabilitation program then very successfully incorporated clinical mental health services and primary care. http://www.cridercenter.org/


Centers for Medicare and Medicaid Services. Georgia-Iowa-Mississippi-Missouri Join Maryland and New Hampshire as CMS Balancing Incentives Grantees. There are now six states receiving Centers for Medicare and Medicaid (CMS) grants under the Affordable Care Act to rebalance their systems toward home and community based services. June 20, 2012.

Montana


AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for support of family caregivers, in order from 1st to 5th were Oregon, Washington, Arizona, Minnesota, and Iowa. The bottom five states for support of family caregivers, in order from 51st to 46th were Oklahoma, Alabama, West Virginia, New York, and Montana.

Nebraska

On March 14, CMS (Centers for Medicare and Medicaid) announced 23 additional Community Based Transitions Program (CCTP) sites. CCTP targets Medicare patients with risk of hospital readmissions. CCTP are community based organization-acute care hospital partnerships focused on providing community based services and supports. The original November 18, 2011 seven sites were: Arizona, Georgia, Illinois, Maine, New Hampshire, and Ohio (2 sites). Added March 14 were 23 sites: Arizona, Arkansas, California, Colorado, Connecticut, Illinois, Massachusetts (2 sites), Michigan (3 sites), Nebraska, New York (4 sites), Ohio, Pennsylvania (3 sites), Texas (2 sites), and Washington (2 sites).

Centers for Medicare and Medicaid Services. Community Based Care Transition Program. Webinar Notes, March 27, 2012. Six States with Program Sites featured: Central Arkansas Care Transitions Program; Elder Services of Berkshire County, Massachusetts; UniNet Healthcare Network, eastern Nebraska; Brooklyn Care Transition Coalition of New York; North Philadelphia Safety Net Partnership, Pennsylvania; and Western Pennsylvania Community Care Transitions Program.


Nevada

Gold, Steve alert – “Comparing States on Access to Community Based Services.” Info Bulletin #354, March 30, 2012. One of the four criteria is HCBS expenditures per capita. The national average is $166.00. Nevada is the lowest at $59.00.


New Hampshire


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Individual Placement and Support (IPS) supported employment helps people with severe mental illness work at regular jobs of their choosing. Although variations of supported employment exist, IPS refers to the evidence-based practice of supported employment.

Dartmouth University has an IPS center and is coordinating sites around the country. [http://www.dartmouth.edu/~ips/](http://www.dartmouth.edu/~ips/)


University of Massachusetts, Institute for Community Inclusion. “State Data: The National Report on Employment Services and Outcomes.” Winter 2011. Connecticut, Louisiana, New Hampshire, Oklahoma, and Washington all reported that more than 40% of individuals receiving day and employment services were receiving integrated employment services. (page 9)

Arizona, Michigan, California, New Hampshire, and Vermont were rated by United Cerebral Palsy as the best Medicaid programs in the nation for serving people with intellectual and other developmental disabilities. Mississippi, Illinois, Arkansas, and Texas were rated the lowest states. United Cerebral Palsy. The Case for Inclusion, 2012. May 2012.

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New Jersey

SAMHSA. Peer Respite Services: Transforming Crisis to Wellness. August 4, 2011 training webinar. Featured were Georgia – Mental Health Consumer Network; New Jersey – Institute for Wellness and Recovery Initiatives; and New York – Projects to Empower and Organize the Psychiatrically Labeled – Hospital Diversion Services.


“Cash and Counseling” or “Independent Choices” programs - initiatives to fulfill “participant-directed,” “consumer-directed,” and “self-directed” approaches. Independent Choices allow the individual enrollee to hire and fire their personal attendants and aides (referred to as employer-authority) or manage monetary allowances on personal assistants or necessary goods and services (such as assistive technologies, transportation, home modifications) (referred to as budget authority). Enrollees may also choose agency delivered services. As of November 2011, there were 298 Participant-Directed Services programs in the U.S., with at least one program in every state. Total enrollment was 810,000 people with 59% of participants in California. The Affordable Care Act (ACA) expends this model through the “Community First-Choice” authority. Arkansas was the first program in the nation, followed by Florida and New Jersey. [Arkansas Department of Human Services; Doty, et al; National Resource Center for Participant-Directed Services.]

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Centers for Medicare and Medicaid Services. Center for Medicare and Medicaid Innovation. Comprehensive Primary Care Initiative: Memorandums of Understanding. June 6, 2012. This is a multi-payer initiative fostering collaboration between public and private health care payers to strengthen primary care, Selected markets are in Arkansas, Colorado, Kentucky, New Jersey, New York, Ohio, Oklahoma, and Oregon.

New Mexico

New Mexico Governor’s Commission on Disability. Draft Components of an 1115 Waiver: Development of a Comprehensive Long Term Services and Supports Program.


Mathematica analyzed state programs and special needs plans pre-CMS dual demos in Arizona, Maryland, Massachusetts, Minnesota, New Mexico, North Carolina, Oklahoma, Vermont, and Virginia. Five findings were: Strong state political and organizational leadership and commitment over time; building enrollment is a major problem; most potential short-time savings accrue to Medicare, rather than Medicaid; program structures vary but the core elements of care coordination and multidisciplinary teams are similar; and programs are hindered by conflicting Medicare and Medicaid rules. Mathematica Policy Research. “Managing the Care of Dual Eligible Beneficiaries: A Review of Selected State Programs and Special Needs Plans.” June 2011.

New York


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- National Council on Disability. “Analysis and Recommendations for the Implementation of Managed Care in Medicaid and Medicare Programs for People with Disabilities.” February 2012. New York carves out institutional services from its managed LTSS design. Both NCD and CCD oppose such carve outs, for taking the most expensive support alternative out of the service array.

- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for support of family caregivers, in order from 1st to 5th were Oregon, Washington, Arizona, Minnesota, and Iowa. The bottom five states for support of family caregivers, in order from 51st to 46th were Oklahoma, Alabama, West Virginia, New York, and Montana.

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- Primary Care Home Visits Demo Sites Announced: On April 26, 2012, CMS (Centers for Medicare and Medicaid Services) announced the selection of 16 organizations to provide primary care in the home setting to improve care for people with multiple chronic conditions. The 16 sites are in Delaware, Florida (2), Georgia, Kentucky, Massachusetts, Michigan (2), North Carolina, New York (2), Ohio, Oregon, Texas (2), and Wisconsin.


Thorpe, Jane Hyatt and Katherine Jett Hayes. “A New State Plan Option To Integrate Care and Financing for People Dually Eligible for Medicare and Medicaid.” George Washington University, School of Public Health and Health Services, Department of Health Policy commissioned report by the Association for Community Affiliated Plans (www.communityplans.net) – December 8, 2011. Five state duals demos were summarized by the report – Arizona, Massachusetts, Minnesota, New York, and Wisconsin were summarized. Three New York completely voluntary programs are described – Medicaid Advantage (concurrent enrollment in a Medicare SNP and Medicaid managed care plan), Medicaid Advantage Plus (for those people requiring nursing home level of care), and five PACE (Programs for All Inclusive Care for the Elderly) sites.

National Association of State Mental Health Program Directors. Reclaiming Lost Decades: The Role of State Behavioral Health Agencies in Accelerating the Integration of Behavioral Healthcare and Primary Care to Improve the Health of People with Serious Mental Illness. May 4, 2012. With implementation of a new “Western New York State Care Coordination Program” – New York saw an immediate 46% decrease in emergency department visits per Medicaid enrollee, a 53% reduction in days spent in the hospital, and 92% lower costs for inpatient services, compared to counties without this program.

Centers for Medicare and Medicaid Services. Center for Medicare and Medicaid Innovation. Comprehensive Primary Care Initiative: Memorandums of Understanding. June 6, 2012. This is a multi-payer initiative fostering collaboration between public and private health care payers to strengthen primary care, Selected markets are in Arkansas, Colorado, Kentucky, New Jersey, New York, Ohio, Oklahoma, and Oregon.

North Carolina


Medicaid-Medicare eligible Beneficiaries – Centers for Medicare and Medicaid Services – State proposals publicly available: Illinois, Massachusetts, Michigan, Minnesota, New York, North Carolina, Ohio, Oklahoma, Oregon, Vermont, Washington, Wisconsin

On March 29, Disability Rights North Carolina and National Health Law Project reported that a Federal District Court ordered the State of North Carolina to halt reductions to home and community based services and restore lost services until the state Medicaid agency and its managed care contractor, Piedmont Behavioral Healthcare, comply with beneficiary notification requirements.

National Council on Disability. “Analysis and Recommendations for the Implementation of Managed Care in Medicaid and Medicare Programs for People with Disabilities.” February 2012. North Carolina carves out institutional services from its managed LTSS design. Both NCD and CCD oppose such carve outs, for taking the most expensive support alternative out of the service array.


Medicaid partners with the North Carolina Housing Finance Agency the people with disabilities receiving rent subsidies received Section 1915 © waiver case management and mental health services.

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Commonwealth Care Alliance, Massachusetts; Minnesota Health Care Homes (state Medicaid program); Community Care of North Carolina; Summa Health System, Ohio; and Community Health Partnership in Wisconsin.


- Thorpe, Jane Hyatt and Katherine Jett Hayes. “A New State Plan Option To Integrate Care and Financing for People Dually Eligible for Medicare and Medicaid.” George Washington University, School of Public Health and Health Services, Department of Health Policy commissioned report by the Association for Community Affiliated Plans (www.communityplans.net) – December 8, 2011. Recommends North Carolina Division of Medical Assistance medical necessity definition: “Those services which are in the opinion of the treating physician, reasonable and necessary in establishing a diagnosis and providing palliative, curative, or restorative treatment for physical and/or mental health conditions…Each service must be sufficient in amount, duration, and scope to reasonably achieve its purpose.”

- NAMI. Integrating Mental Health and Pediatric Primary Care: A Family Guide. November 2011. NAMI recommends three programs that have successfully integrated mental health and pediatric primary care programs – Cherokee Health Systems, Tennessee; Massachusetts Child Psychiatry Access Project; and North Carolina Center for Excellence for Integrated Care.

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North Dakota

- Gold, Steve alert – “Comparing States on Access to Community Based Services.” Info Bulletin #354, March 30, 2012. One of the four criteria is % of HCBS to total Medicaid long term care expenditures. The national average is 45%. Three states – Illinois, Mississippi, North Dakota – have the lowest at 30%.

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Northern Mariana Islands

Ohio


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**Oklahoma**


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University of Massachusetts, Institute for Community Inclusion. “State Data: The National Report on Employment Services and Outcomes.” Winter 2011. Connecticut, Louisiana, New Hampshire, Oklahoma, and Washington all reported that more than 40% of individuals receiving day and employment services were receiving integrated employment services. (page 9)

National Association of State Directors of Developmental Disabilities Services (NASDDS)-Human Services Research Institute (HSRI) National Core Indicators (NCI) Program. 2009-2010

States with the highest proportion of people having a job in the community were DC, Georgia, Maine, Oklahoma, and Wyoming. However, only 52% of the people’s hourly earnings were at or above the state’s minimum wage.

United Cerebral Palsy. The Case for Inclusion, 2012. May 2012. States are rated on “four key aspects of a high functioning Medicaid program” — (1) participation in their communities, (2) have satisfying lives and valued social roles, (3) have sufficient access to needed support and control over that support to contribute to the lifestyles they desire, and (4) live in safe and healthy environments. Only 15 states supported a large share of families through family supports. More than a quarter of a million people (268,000 nationwide) are on waiting lists for home and community based services. Just nine states have at least one third (33%) of individuals with ID/DD working in competitive employment. These states are Alaska, Connecticut, Delaware, Maryland, Michigan, Oklahoma, Pennsylvania, Vermont, and Washington.

Centers for Medicare and Medicaid Services. Center for Medicare and Medicaid Innovation. Comprehensive Primary Care Initiative: Memorandums of Understanding. June 6, 2012. This is a multi-payer initiative fostering collaboration between public and private health care payers to strengthen primary care, Selected markets are in Arkansas, Colorado, Kentucky, New Jersey, New York, Ohio, Oklahoma, and Oregon.

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Oregon


- Oregon – Cascadia Behavioral Health Center, Benton County. - Cascadia Peer Wellness Program

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Pennsylvania

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- Centers for Medicare and Medicaid Services. Community Based Care Transition Program. Webinar Notes, March 27, 2012. Six States with Program Sites featured: Central Arkansas Care Transitions Program; Elder Services of Berkshire County, Massachusetts; UniNet Healthcare
Network, eastern Nebraska; Brooklyn Care Transition Coalition of New York; North Philadelphia Safety Net Partnership, Pennsylvania; and Western Pennsylvania Community Care Transitions Program.


As part of its Medicaid mental health managed care initiatives, Massachusetts and Philadelphia, Pennsylvania financed third party, independent, consumer and family directed consumer satisfaction monitoring teams. The teams focus on documented dis-satisfaction and regularly meet with health plans to resolve areas of dis-satisfaction. [NAMI and Ross]

United Cerebral Palsy. The Case for Inclusion, 2012. May 2012. States are rated on “four key aspects of a high functioning Medicaid program” – (1) participation in their communities, (2) have satisfying lives and valued social roles, (3) have sufficient access to needed support and control over that support to contribute to the lifestyles they desire, and (4) live in safe and healthy environments. Only 15 states supported a large share of families through family supports. More than a quarter of a million people (268,000 nationwide) are on waiting lists for home and community based services. Just nine states have at least one third (33%) of individuals with ID/DD working in competitive employment. These states are Alaska, Connecticut, Delaware, Maryland, Michigan, Oklahoma, Pennsylvania, Vermont, and Washington.


Puerto Rico

Rhode Island


“Enhanced PCCM (primary care case management) can serve “as an alternative to risk-based managed care.” The Kaiser Commission...


South Carolina


South Dakota

- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for choice of setting and provider, in order from 1st to 5th were Alaska, Washington, Minnesota, Vermont, and Oregon. The bottom five states for choice of setting and provider, in order from 51st to 46th were Mississippi, Alabama, Delaware, South Dakota, and Tennessee.


Tennessee


- Five states were interviewed by the Center for Health Care Strategies regarding managed LTSS for Medicaid-Medicare

- See the “Policy and Advocacy Recommendations” section for a complete list of 10 Center for Health Care Strategies milestones for managed LTSS. April 13, 2012. One of the 10 was: engage stakeholders to achieve buy-in. Tennessee, Texas, and Wisconsin were cited as examples.

- See the “Policy and Advocacy Recommendations” section for a complete list of 10 Center for Health Care Strategies milestones for managed LTSS. April 13, 2012. One of 10 was to structure benefits to appropriately incentivize the right care. Tennessee Choices was cited as an example.

- See the “Policy and Advocacy Recommendations” section for a complete list of 10 Center for Health Care Strategies milestones for managed LTSS. April 13, 2012. One of 10 was robust oversight contractor/monitoring requirements. Tennessee’s monthly HCBS monitoring was cited as an example.

- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for choice of setting and provider, in order from 1st to 5th were Alaska, Washington, Minnesota, Vermont, and Oregon. The bottom five states for choice of setting and provider, in order from 51st to 46th were Mississippi, Alabama, Delaware, South Dakota, and Tennessee.

- Cherokee Health Center in Tennessee is a national model for integration of mental health and primary care. It is essentially an integrated community health and community mental health center. [http://www.cherokeehealth.com/](http://www.cherokeehealth.com/)

- The Creating Homes Initiative in Tennessee is a national model for developing a continuum of housing options for people with serious mental illness or co-occurring disorders. [http://state.tn.us/mental/recovery/CHIpage.html](http://state.tn.us/mental/recovery/CHIpage.html) Working with local community housing developers and other stakeholders in partnership with seven Regional Housing Facilitators, the program has leveraged to date more than $101 million in federal, state, local, public, private, traditional, and non-traditional funding sources and has successfully created more than 4,600 permanent, safe, affordable, quality, permanent housing options for Tennesseans diagnosed with mental illness and co-occurring disorders.


- NAMI. Integrating Mental Health and Pediatric Primary Care: A Family Guide. November 2011. NAMI recommends three programs that have successfully integrated mental health and pediatric primary care programs – Cherokee Health Systems, Tennessee; Massachusetts Child Psychiatry Access Project; and North Carolina Center for Excellence for Integrated Care.

**Texas**

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- National Academy of State Health Policy and Health Resources and Services Administration. Six State Teams for Medicaid-Safety Net Learning Collaborative Selected. April 10, 2012. The states were Alaska, Iowa, Maryland, Maine, Minnesota, and Texas.

- Five states were interviewed by the Center for Health Care Strategies regarding managed LTSS for Medicaid-Medicare eligibles. The states were Arizona, Hawaii, Tennessee, Texas, and Wisconsin. National Council on Aging. NCOA Friday Morning Collaborative webinar, “Managed Long Term Services and Supports: An Overview of Key Issues and Guiding Principles.” Sarah Barth, Center for Health Care Strategies. April 13, 2012.

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- Money Follows the Person Program Moving at “Glacial Pace” On May 24, Kaiser Health News summarized a report by Mathematica Policy Research that the CMS Medicaid state option program, Money Follows the Person, has been slow to fully implement. Money Follows the Person supports people who have transitioned back to the community from a variety of institutions. Major reasons for slow delivery are the lack of affordable and accessible housing, lack of community based work force, and not enough life-skills training. Texas has made good progress and California has been very slow because of fragmented and inadequate infrastructure. Nationwide, 14% of the elderly and 10% of people with physical disabilities returned to the institution within a year. The essence of the challenge — states need the CMS dollars to make the investment in the infrastructure; states don’t get the extra federal dollars until people are moved to the community; states can’t move people until they have the infrastructure. Kaiser Health News. “States Struggling To Meet Community Living Goals.” [Money Follows the Person — review of Mathematica Policy Research] May 25, 2012.


- Arizona, Michigan, California, New Hampshire, and Vermont were rated by United Cerebral Palsy as the best Medicaid programs in the nation for serving people with intellectual and other developmental disabilities. Mississippi, Illinois, Arkansas, and Texas were rated the lowest states. United Cerebral Palsy. The Case for Inclusion, 2012. May 2012.
Utah


Vermont


- AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for choice of setting and provider, in order from 1st to 5th were Alaska, Washington, Minnesota, Vermont, and Oregon. The bottom five states for choice of setting and provider, in order from 51st to 46th were Mississippi, Alabama, Delaware, South Dakota, and Tennessee.


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- United Cerebral Palsy. The Case for Inclusion, 2012. May 2012. States are rated on “four key aspects of a high functioning Medicaid program” – (1) participation in their communities, (2) have satisfying lives and valued social roles, (3) have sufficient access to needed support and control over that support to contribute to the lifestyles they desire, and (4) live in safe and healthy environments. Only 15 states supported a large share of families through family supports. More than a quarter of a million people (268,000 nationwide) are on waiting lists for home and community based services. Just nine states have at least one third (33%) of individuals with ID/DD working in competitive employment. These states are Alaska, Connecticut, Delaware, Maryland, Michigan, Oklahoma, Pennsylvania, Vermont, and Washington.

- RESNA – Nell Bailey May 24, 2012 memo to Clarke Ross – Assistive Technology and State Medicaid programs. Many of the state AT programs refurbish used equipment (AT, DME, and computers) and make them available to individuals with disabilities that can’t afford the technology otherwise. In a couple of states (Kansas and Vermont), they are working with state Medicaid to provide reused equipment. Kansas: ATK provides quality used devices through two efforts. KEE is a reuse partnership between Kansas Health Policy Authority and ATK. Through KEE, eligible Kansans can get quality, refurbished durable medical equipment such as manual and power wheelchairs, patient lifts, electronic hospital beds, shower chairs, communication devices, and other health devices. For Vermont, go to http://atp.vermont.gov/get-at-stuff and scroll down to the bottom of the page to see what they are doing and what’s covered.

- Mathematica analyzed state programs and special needs plans pre-CMS dual demos in Arizona, Maryland, Massachusetts, Minnesota, New Mexico, North Carolina, Oklahoma, Vermont, and Virginia. Five findings were: Strong state political and organizational leadership and commitment over time; building enrollment is a major problem; most potential short-time savings accrue to Medicare, rather than Medicaid; program structures vary but the core elements of care coordination and multidisciplinary teams are similar; and programs are hindered by conflicting Medicare and Medicaid rules. Mathematica Policy Research. “Managing the Care of Dual Eligible Beneficiaries: A Review of Selected State Programs and Special Needs Plans.” June 2011.
Virgin Islands

Virginia

- On March 30, the Bazelon Center on Mental Health Law announced that 50 organizations have come together to ensure Virginia implementation of an agreement with the Department of Justice to deliver home and community based services.


- Mathematica analyzed state programs and special needs plans pre-CMS dual demos in Arizona, Maryland, Massachusetts, Minnesota, New Mexico, North Carolina, Oklahoma, Vermont, and Virginia. Five findings were: Strong state political and organizational leadership and commitment over time; building enrollment is a major problem; most potential short-time savings accrue to Medicare, rather than Medicaid; program structures vary but the core elements of care coordination and multidisciplinary teams are similar; and programs are hindered by conflicting Medicare and Medicaid rules. Mathematica Policy Research. “Managing the Care of Dual Eligible Beneficiaries: A Review of Selected State Programs and Special Needs Plans.” June 2011.

Washington


- On March 14, CMS announced 23 additional Community Based Transitions Program (CCTP) sites. CCTP targets Medicare patients with risk of hospital readmissions. CCTP are community based organization-acute care hospital partnerships focused on providing community based services and supports. The original November 18, 2011 seven sites were: Arizona, Georgia, Illinois, Maine, New Hampshire, and Ohio (2 sites). Added March 14 were 23 sites: Arizona, Arkansas, California, Colorado, Connecticut, Illinois, Massachusetts (2 sites), Michigan (3 sites), Nebraska, New York (4 sites), Ohio, Pennsylvania (3 sites), Texas (2 sites), and Washington (2 sites).


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AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states for support of family caregivers, in order from 1st to 5th were Oregon, Washington, Arizona, Minnesota, and Iowa. The bottom five states for support of family caregivers, in order from 51st to 46th were Oklahoma, Alabama, West Virginia, New York, and Montana.


U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Federal Financing of Supported Employment and Customized Employment for People with Mental Illnesses: Final Report. February 2011. Four states were analyzed for their recent success and experience with implementing supported employment (SE) programs, partially financed with Medicaid. The states were Illinois, Kansas, Maryland, and Washington. The rehabilitation and targeted case management Medicaid options and the Section 1915 HCBS options finance individual supports that are partially related to employment goals. Maryland also authorizes Medicaid “buy-in” for people with disabilities who work.

Gray, Jennifer A.; Jennifer L. Zimmerman; and James Rimmer. “Built Environment Instruments for Walkability, Bikeability, and Recreation: Disability and Universal Design Relevant?” In: Disability and Health Journal. 5 (2) April 2012. 87-101. The article recommends the King County, Washington, “Active Community Checklist,” an urban area use checklist that includes promoting built environment access for people with disabilities.

University of Massachusetts, Institute for Community Inclusion. “State Data: The National Report on Employment Services and Outcomes.” Winter 2011. Connecticut, Louisiana, New Hampshire, Oklahoma, and Washington all reported that more than 40% of individuals receiving day and employment services were receiving integrated employment services. (page 9)


United Cerebral Palsy. The Case for Inclusion, 2012. May 2012. States are rated on “four key aspects of a high functioning Medicaid program” – (1) participation in their communities, (2) have satisfying lives and valued social roles, (3) have sufficient access to needed support and control over that support to contribute to the lifestyles they desire, and (4) live in safe and healthy environments. Only 15 states supported a large share of families through family supports. More than a quarter of a million people (268,000 nationwide) are on waiting lists for home and community based services. Just nine states have at least one third (33%) of individuals with ID/DD working in competitive employment. These states are Alaska, Connecticut, Delaware, Maryland, Michigan, Oklahoma, Pennsylvania, Vermont, and Washington.

West Virginia

AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states, in order from 1st to 5th were Minnesota, Washington, Oregon, Hawaii, and Wisconsin. The bottom five states, in order from 51st to 46th were Mississippi, Alabama, West Virginia, Oklahoma, and Indiana.

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Wisconsin


Medicaid-Medicare eligible Beneficiaries – Centers for Medicare and Medicaid Services – State proposals publicly available: Illinois, Massachusetts, Michigan, Minnesota, New York, North Carolina, Ohio, Oklahoma, Oregon, Vermont, Washington, Wisconsin


The Medicaid and CHIP Payment and Access Commission (MACPAC) – “Several states have started designing strategies for measuring quality of care specifically for Medicaid enrollees with disabilities and other high-need, high-cost populations.” California is considering a dashboard of 13 adult measures for Medicaid managed care plans. Missouri amended its state plan for health homes to include behavioral health quality measures. Michigan is considering disability quality measures in its duals demonstration. Wisconsin is using “personal experience outcomes” from consumers. [MACPAC, Report to the Congress on Medicaid and CHIP, March 2012. Pages 65-67]


National Council on Aging. Home and Community Services Crossroads discussion list. April 10, 2012. Mike Bachhuber: “Wisconsin has a couple of relatively successful managed care programs that include HBBS.” These are WI Family Care Partnership and WI Family Care.

Five states were interviewed by the Center for Health Care Strategies regarding managed LTSS for Medicaid-Medicare eligibles. The states were Arizona, Hawaii, Tennessee, Texas, and Wisconsin. National Council on Aging. NCOA Friday Morning Collaborative webinar, “Managed Long Term Services and Supports: An Overview of Key Issues and Guiding Principles.” Sarah Barth, Center for Health Care Strategies. April 13, 2012.

See the “Policy and Advocacy Recommendations” section for a complete list of 10 Center for Health Care Strategies mileposts for managed LTSS. April 13, 2012. One of the 10 was: engage stakeholders to achieve buy-in. Tennessee, Texas, and Wisconsin were cited as examples.

See the “Policy and Advocacy Recommendations” section for a complete list of 10 Center for Health Care Strategies mileposts for managed LTSS. April 13, 2012. One of the 10 was use of a uniform assessment tool. The Wisconsin Long Term Care Functional Screen was cited as an example.

See the “Policy and Advocacy Recommendations” section for a complete list of 10 Center for Health Care Strategies mileposts for managed LTSS. April 13, 2012. One of 10 was the need for focused performance measurement. The Wisconsin PEONIES (personal interview) was cited as an example.

AARP Public Policy Institute. Raising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. September 2011. The top five states, in order from 1st to 5th were Minnesota, Washington, Oregon, Hawaii, and Wisconsin. The bottom five states, in order from 51st to 46th were Mississippi, Alabama, West Virginia, Oklahoma, and Indiana.
The American Hospital Association has proposed 12 core elements for successful care management of vulnerable seniors, including Medicaid-Medicare eligible. These are hospital-based programs focused on seniors with chronic illness. The 12 core elements are (1) complete comprehensive assessment and reassessment, (2) periodic visits, (3) protocol-based planning, (4) person-centered care principles and planning, (5) team-based management centered on primary care, (6) data sharing and integrated information systems, (7) alignment of financial incentives, (8) networks and community partnerships, (9) non-health care services provided (such as transportation), (10) home based services, (11) center-based “day care,” and (12) cultural competency and equity standards. The AHA identified 10 hospital based “promising models.” One the 10 is the Acute Care Elders Tracker program at Aurora Health Care, Milwaukee. Aurora provides six of the 12 elements (#1,3,4,5,6,7).

Primary Care Home Visits Demo Sites Announced: On April 26, 2012, CMS announced the selection of 16 organizations to provide primary care in the home setting to improve care for people with multiple chronic conditions. The 16 sites are in Delaware, Florida (2), Georgia, Kentucky, Massachusetts, Michigan (2), North Carolina, New York (2), Ohio, Oregon, Texas (2), and Wisconsin.

Agency for Healthcare Research and Quality. “Coordinating Care for Adults with Complex Care Needs in the Patient-Centered Medical Home: Challenges and Solutions.” Prepared by Mathematica Policy Research. January 2012. Five PCMHs were selected for review: Commonwealth Care Alliance, Massachusetts; Minnesota Health Care Homes (state Medicaid program); Community Care of North Carolina; Summa Health System, Ohio; and Community Health Partnership in Wisconsin.


Thorpe, Jane Hyatt and Katherine Jett Hayes. “A New State Plan Option To Integrate Care and Financing for People Dually Eligible for Medicare and Medicaid.” George Washington University, School of Public Health and Health Services, Department of Health Policy commissioned report by the Association for Community Affiliated Plans (www.communityplans.net) – December 8, 2011. Five state duals demos were summarized by the report – Arizona, Massachusetts, Minnesota, New York, and Wisconsin were summarized.


Wyoming


National Association of State Directors of Developmental Disabilities Services (NASDDS)-Human Services Research Institute (HSRI) National Core Indicators (NCI) Program. 2009-2010

States with the highest proportion of people having a job in the community were DC, Georgia, Maine, Oklahoma, and Wyoming. However, only 52% of the people’s hourly earnings were at or above the state’s minimum wage.
Quality and Performance Measures

Appropriate Standardized Quality and Performance Measures Are Generally Not Yet Available

Independent Third Party Consumer and Family Monitoring Teams Are and Should be Formed and Utilized

Measuring Healthcare Quality for People Medicaid-Medicare eligible: Measures Are Not Yet Available. The National Quality Forum (NQF) Measure Applications Partnership (MAP) is a public-private partnership for providing input to HHS (Department of Health and Human Services) on performance measures in federally financed health services programs. MAP has published its year one status report on performance measures for people Medicaid-Medicare eligible. The report is here: [http://www.qualityforum.org/map/](http://www.qualityforum.org/map/)

1. “MAP’s efforts to compile a set of performance measures appropriate for assessing and improving the quality of care for dual eligible beneficiaries was constrained by gaps in available measures,” page 21

2. “The lengthy list of measure development gaps reveals that many concepts considered core to improving the quality of care and supports for dual eligible beneficiaries are not yet measurable,” page 23

3. Conclusion, page 32: “Much work remains before MAP’s vision for high quality care for dual eligible beneficiaries will be fully realized.”

MACPAC: “The Secretary (of HHS), in partnership with the states, should update and improve quality assessment for Medicaid enrollees with disabilities. Quality measures should be specific, robust, and relevant for this population. Priority should be given to quality measures that assess the impact of current programs and new service delivery innovations on Medicaid enrollees with disabilities.”

Before implementing managed care of long term services and supports, the state must develop and have in place a comprehensive quality management system that continuously gathers, evaluates, and monitors performance data of contractors and subcontractors. Independent third party consumer and family monitoring teams should be formed and utilized as part of the quality management system to perform on-going evaluations and assessments of the effectiveness of managed care in supporting beneficiaries in living full, healthy, participatory lives in their communities. Quality management data must be transparent and readily available to the public.

States should adopt qualitative data metrics on the managed care entity’s ability to coordinate acute and post acute care, as well as the full complement of Medicaid waiver services, including home and community based services and supports. For instance, managed care plans must be able to demonstrate the ability to provide quality services and attain high consumer satisfaction levels. Managed care plans should routinely report their performance using such metrics. Failure to reach a certain quality threshold should result in meaningful enforcement action by the state to correct the problem. Results must be shared with stakeholders and the general public within reasonable time frames to allow for outside analysis and evaluation.

The dearth of measures to assess the quality of LTSS is of great concern and reinforces a belief that including LTSS for people with disabilities in integrated coordinated demonstrations is premature. Until valid reliable quality measures are adopted, states should not turn over responsibility for those services to private entities. States should “include data by disability type about unmet needs, delays in service, and utilization of services.”

The Medicaid Disability Managed Care Collaborative and Consortium for Citizens with Disabilities (CCD) ad hoc Workgroup on State Medicaid Implementation co-chairs believe that measures of quality and performance in six areas of interest to consumers with disabilities and their families should be developed and implemented by CMS.
The six measure areas are:

1. Consumer choice and participant-directed services
2. Satisfaction – individual experience with services and supports
3. Percent in employment or meaningful day activity
4. Percent in independent housing – consumer choice, housing appropriateness, stability
5. Integrated primary and specialty care
6. Access to timely and appropriate care

Two existing measurement systems are utilized by some programs that provide long term services and supports for people with intellectual and other developmental disabilities. The National Core Indicators is a project of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and Human Services Research Institute (HSRI). The Personal Outcome Measures is a product of the Council on Quality and Leadership (CQL). The indicators included in these products may provide investigators with building blocks toward development of quality measures that could ascertain whether services ensure consumer choice, participant-direction, and individual satisfaction. National Empowerment Center. Sara Plachta-Elliott and Jonathan Delman. Consumer-Led Evaluation Teams: A Peer-Led Approach to Assessing Consumer Experiences with Mental Health Services. June 2009. Consumer-Led Evaluation Teams are operated independently by consumers and/or family members and evaluate mental health programs by learning about the experiences of program clients. As of 2009, at least four programs operated across the nation – Consumer Quality Team, Maryland; Consumer Quality Initiatives, Massachusetts; Consumer Satisfaction Team, Philadelphia; and Vital Voices for Mental Health, Milwaukee, Wisconsin.
Workers, Unions, and Staffing Considerations

As states develop home and community based services for people with disabilities, state legislators will need to consider staffing, personal assistance, and worker issues. If state owned and operated institutions are involved, organized labor might be a party. Organized labor is also interested in home and community based services. The adequacy of a trained workforce is an issue. The role of family caregivers is an issue. A growing trend is individuals with disabilities directing their own services and supports.

The National Advisory Board (NAB) promotes “home and community based services and supports.” The NAB’s approach is defined using six principles: (1) Enhance Self-Care Through Improved Coordination; (2) Encourage Community Integration and Involvement; (3) Expand Accessibility of Services and Supports; (4) Uphold Personal Preference - Leverage the success of long term service models that promote personal strengths and preferences and preserve dignity of participants; (5) Empower People to Participate in the Economic Mainstream; and (6) Invest in Improved Technology. The role of family caregivers and people with disabilities self-directing their own services and supports are important elements in considering staffing issues to achieve these principles.

The National Resource Center for Participant-Directed Services (NRCPDS) has developed approaches for ensuring participant (person with a disability being provided supports and services) choice and control in order to pursue their objectives of meaningful home and community based living. In addition, NRCPDS and four other organizations have developed with organized labor guiding principles. The guiding principles have three themes: (1) commitment to the participant as the employer of those that provide services and supports to them; (2) recognition that workers assisting the person with a disability have rights and life goals; and (3) an atmosphere of respect is important. These principles are fully consistent with the NAB principles.

With initiatives such as “Cash and Counseling” and Medicaid home and community based waiver programs, many individuals with disabilities recruit, hire, and supervise the workers who provide services and supports, including personal assistance. The need for adequate training of those providing services and supports is great; people with disabilities should be a vital part of the training. State policies should ensure individualized, participant-directed training and supervision.

Families are very important supports for many individuals with disabilities. Supports are needed to maintain the health and improve the quality of life for family caregivers. Workplace policies need to recognize and accommodate family caregiver employees. Comprehensive care coordination that addresses the needs of people with disabilities should meaningfully include family caregivers. At the choice of the individual with a disability, family caregivers may be appropriate as paid assistants.

The potential for worker burnout and isolation is an important challenge. Caregiving is stressful work.

When dealing with organized labor, two national organizations may be involved:

- **American Federation of State, County, and Municipal Employees (AFSCME)**  
  http://www.afscme.org/

- **Service Employees International Union (SEIU)**  
  http://www.seiu.org/
Important Resources:


- **National Alliance for Caregiving**
  http://www.caregiving.org/

- **National Resource Center for Participant-Directed Services**
  www.ParticipantDirection.org

- **National Resource Center for Participant-Directed Services, ADAPT, The Center for Self-Determination of People with Developmental Disabilities, the Service Employees International Union (SEIU), and Topeka Independent Living Center.** “Guiding Principles for Partnerships with Unions and Emerging Worker Organizations When Individuals Direct Their Own Services and Supports.” November 16, 2011.

- **Parent-to-Parent, USA**
  www.p2pusa.org/
Policy Recommendations – National Organizations Utilized

The National Advisory Board has carefully analyzed the public sector long-term services and supports (LTSS), Medicaid, and Medicaid managed care recommendations offered by the following:

- **ADAPT**
  http://www.adapt.org/

- **ADAPT, Texas**
  http://adaptoftexas.org/

- **AAPD - American Association of People with Disabilities**
  http://www.aapd.com/

- **AARP PPI– American Association of Retired Persons, Public Policy Institute**
  http://www.aarp.org/research/ppi/

- **Agency for Healthcare Research and Quality**
  http://www.ahrq.gov/

- **American Hospital Association**
  http://www.aha.org/

- **Bazelon Center for Mental Health Law**
  http://www.bazelon.org/

- **Peter Bowers, M.D., Medical Director, Payment Innovation Strategy, Wellpoint – see tool on policy resources**

- **Center for Health Care Strategies**
  http://www.chcs.org/

- **Centers for Medicare and Medicaid - The CMS April 27, 2012 Community First Choice final rules**
  http://www.cms.gov/

- **Commonwealth Fund**
  http://www.commonwealthfund.org/

- **Consortium for Citizens with Disabilities**
  http://www.c-c-d.org/

- **Consumer Partnership for e-Health**
  http://www.nationalpartnership.org/site/PageServer?pagename=issues_health_IT_CPeH
Dartmouth Psychiatric Research Center
http://prc.dartmouth.edu/

Disability Rights Education and Defense Fund
http://www.dredf.org/

Georgetown University Health Policy Institute
http://ihcrp.georgetown.edu/


Institute for Patient and Family Centered Care
http://www.ipfcc.org/

Kaiser Commission on Medicaid and the Uninsured
http://www.kff.org/about/kcmu.cfm

John Kregel. “Work Incentives Planning and Assistance: Assisting Beneficiaries To Obtain Employment and Reduce Dependence on SSA Benefits.” See tool on policy resources

MACPAC – Medicaid and CHIP Payment and Access Commission
http://www.macpac.gov/

Mathematica Policy Research
http://www.mathematica-mpr.com/

Monika Milta, Karen Bogen, Linda Long-Bellil, and Dennis Heaphy. “Unmet Needs for Home and Community Based Services Among Persons with Disabilities in Massachusetts.” See tool on policy resources

NAB – National Advisory Board – individual members

NAMI – National Alliance on Mental Illness
http://www.nami.org/

NASUAD – National Association of States United for Aging and Disability
http://www.nasuad.org/

National Council for Independent Living
http://www.ncil.org/

National Council on Disability
http://www.ncd.gov/
- National Disability Leadership Alliance
  http://www.disabilityleadership.org/

- National Quality Forum
  http://www.qualityforum.org/Home.aspx

- National Resource Center for Participant-Directed Services
  http://www.bc.edu/schools/gssw/nrcpds//

- National Senior Citizens Law Center
  http://www.nsclc.org/

- New Mexico Governor's Commission on Disability
  http://www.gcd.state.nm.us/

- Patient-Centered Primary Care Collaborative
  http://www.pcpcc.net/

- RESNA - Rehabilitation Engineering and Assistive Technology Society of North America
  www.resna.org

- SAMHSA – Substance Abuse and Mental Health Services Administration
  www.samhsa.gov

- The Arc
  http://www.thearc.org/

- U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation
  http://www.hhs.gov/about/orgchart/aspe.html

- University of Massachusetts, Institute for Community Inclusion
  http://www.communityinclusion.org/
References – Policy Recommendations

AAPD – American Association of People with Disabilities.
- David Heymsfeld Blog – “Advocates Should Take Advantage of Opportunities To Participate in Developing and Implementing Managed Care Programs for Medicaid.” May 10, 2012.

AARP Public Policy Institute.
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The National Advisory Board on Improving Health Care Services for Seniors and People with Disabilities is composed of distinguished and culturally diverse community advocates, health care experts, and academics who provide guidance and policy recommendations for improving programs and services for seniors and people with disabilities. As a Board, we are people with disabilities; children of aging parents; parents of children and adults with disabilities; and sisters, brothers, spouses, children, and friends of people with disabilities. We represent millions of Americans with disabilities and seniors and their family members, who have struggled with the complexities of our fragmented health care system. Each of us brings a personal perspective to the subject of long term care because each of us has personal experience with it. We, individually and collectively, have worked along with other Americans to overcome the many hurdles to obtain the services we need to live successfully in our communities—hurdles such as the lack of coordination between acute and long term services and supports, antiquated systems and policies, and lack of infrastructure development for long term services. The National Advisory Board would like to thank Amerigroup Corporation for funding the work on this project. Amerigroup Corporation, headquartered in Virginia Beach, Virginia, improves health care access and quality for the financially vulnerable, seniors, and people with disabilities by developing innovative managed health services for the public sector. Through its subsidiaries, Amerigroup Corporation serves approximately 2.7 million people in Florida, Georgia, Louisiana, Maryland, Nevada, New Jersey, New Mexico, New York, Ohio, Tennessee, Texas, Virginia, and Washington.

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The Honorable Jane Woods, CCHHS Community Liaison for State Health Policy and Community Development, College of Health and Human Services, George Mason University, Department of Health Administration and Policy; Former State Senator of Virginia
GLOSSARY OF TERMS

A

Affirmative Obligation (tool 5) – Under Olmstead, states are required to assist people with disabilities to live in their home and community.

Assistive Technology (tool 27, pg 2) – the Assistant Technology Act of 1998 defines this as any item, piece of equipment or product system that is used to increase, maintain or improve functional capabilities of individuals with disabilities.

B

Built Environment (tool 27, pg. 3) – These are human-made structures that may facilitate or impede an individual’s ability to be physically active.

C

Categorically Needy (tool 7) – Applied to every state in the Medicaid program, categorically needy are individuals who fall into a specific category of mandatory Medicaid eligibility established by the federal government. These individuals include: pregnant women and children under certain income levels, caretakers of children under certain income levels, persons receiving Supplemental Security Income (SSI) and persons residing in medical institutions under certain income levels. In order to receive federal funding, states must provide Medicaid coverage to these categories of individuals.

Centers for Medicare and Medicaid – Within the United States Department of Health and Human Services, Centers for Medicare and Medicaid (CMS) is responsible for the administration of several key federal health care programs. In addition to Medicare, the federal health insurance program for seniors is responsible for Medicaid, the federal needs-based program. CMS oversees the Children’s Health Insurance Program (CHIP), the Health Insurance Portability and Accountability Act (HIPPA) and the Clinical Laboratory Improvement Amendments (CLIA).

Community-based Transition’s Program – Community-Based Transition’s Program (CCTP) is a community-based organization and acute care hospital partnership focused on providing community-based services and supports.

Comorbid Conditions (tool 6, pg. 2) – This refers to Medicaid-only enrollees who qualify on the basis of a disability. Comorbidities include: mental illness, cardiovascular disease and central nervous system diseases.

Comparability of Services (tool 8) – Defined in The Medicaid Glossary of Terms, the comparability requirement provides that medical assistance available to any eligible individual shall not be less in amount, duration or scope than the medical assistance made available to any other individual. This requirement ensures equity of health care in two ways. First, it assures that the services provided to individuals who are categorically eligible for Medicaid are comparable to those provided to the medically needy. Second, it ensures that services are comparable among individuals within the group of beneficiaries who are categorically eligible for Medicaid.

Coordination (tool 17) – This term claims that the secretary of the Department of Health and Human Services and the states should accelerate the development of program innovations that support high-quality, cost-effective care for persons with disabilities, particularly those with Medicaid-only coverage.

D

Data Integration (tool 1) – This involves combining data residing in different sources and providing users with a unified view of this information. In this case, data integration refers to a universal understanding of services through the use of health information exchange. Dignity of Risk (tool 23; pg. 3) - Respecting each individual’s autonomy and self-determination (or dignity) to make choices for himself or herself.

Dually Eligible (tool 6, pg. 2, tool 17) – Plans often called “dual” or “dual eligible” are designed for people who qualify for both Medicare and Medicaid. These plans include all Medicare Part A (hospital stay) and Part B (doctor visit) benefits and Part D (prescription drug coverage). For people with limited incomes, these plans may offer better health care coverage than original Medicare and a separate Part D plan.

F

Freedom of Choice Providers (tool 8) – States may exclude providers from participating in Medicaid under certain conditions, and in some situations, federal law requires exclusion. States are not, however, permitted to exclude providers from the program solely on the basis of
the range of medical services they provide. Under federal law, Medicaid beneficiaries may obtain medical services “from any institution, agency, community pharmacy or person qualified to perform the service or services required . . . who undertakes to provide him such services.” (Section 1902(a)(23) of Title XIX of the Social Security Act). This provision is often referred to as the “any willing provider” or “free choice of provider” provision.

H

Health Information Exchange (tool 19) – Health Information Exchange (HIE) is the mobilization of healthcare information electronically across organizations within a region, community, health plans and delivery systems.

Home- and Community-based Services (tool 8) – This term includes a range of personal, support and health-related services provided in the person’s home or community to help the individual live as independently as possible.

Housing First (tool 10) – CMS rule that states housing should not be conditioned upon acceptance of services. This requirement has received widespread acceptance as a method promoting independence, choice and responsibility.

I

Improved Coordination (pg. 2, #17) – This refers to the transformation of America’s health care system from one that focuses on episodic illnesses to one that assists individuals in self-managing their whole health with the support of providers and communities.

Independent Living Model (tool 33) – All long-term services and supports programs should use the concepts fundamental to this model. The delivery of community disability services and supports uses an independent living approach that focuses on the strengths of an individual and seeks avoidance of dependence on professional direction. This model accepts disability as a common part of the human condition and focuses on what a person is able to do and what they desire to do.

Integrated Setting (tool 5) – This setting allows individuals to live in their own home, pursue employment and education in their community and spend time with their family and friends. An integrated setting enables individuals with disabilities to interact with individuals without disabilities to the fullest extent possible.

L

Long-term Services and Supports (tool 6, pg. 2) – Long-Term Services and Supports (LTSS) area range of services and supports required by individuals with significant disabilities to live at home with the supports they need, fully participating in their communities and living satisfying and meaningful lives. These services and supports are intended to meet personal and health-related needs over long periods of time.

M

Managed Care (tool 8) – As defined in the Medicaid Glossary of Terms, over time, state Medicaid programs have migrated toward managed care as the preferred strategy to not only improve access and accountability and reduce costs, but also achieve budget predictability. Many states chose to build upon voluntary managed care programs by enrolling beneficiaries on a mandatory basis into capitated managed care programs under 1915(b) freedom of choice or Section 1115 of the Social Security Act managed care demonstration waivers.

Medicaid and Children’s Health Insurance Program Payment and Access Commission – Established in the CHIP Reauthorization Act of 2009, the Medicaid and CHIP Payment and Access Commission (MACPAC) reviews state and federal Medicaid and CHIP access and payment policies making recommendations to Congress, the secretary of the United States Health and Human Services Department (HHS) and the states on a range of issues affecting Medicaid and CHIP populations, including health care reform.

Medical Model (tool 33) – Traditional managed care programs and health insurance programs rely on the medical model and place a focus on physical or mental impairment and lack of abilities. The medical model views a person with a disability as sick and needing to be fixed.

Medically Needy (tool 1) – States can cover certain persons determined as “medically needy.” These people have too much money to be eligible as categorically needy, but have significant medical needs. If a state has a medically needy program, they must cover pregnant women through a 60 day postpartum period, children under age 18, certain newborns and certain blind persons.
Money Follows the Person – This is a program that supports people who have transitioned back to the community from a variety of institutions.

Patient and Family Centered Services and Supports (tool 23, pg. 2) – This is an approach to the planning, delivery and evaluation of healthcare grounded in the mutually beneficial partnerships among healthcare providers, consumers and families. Patient-centered Medical Home (tool 17) - Also known as “health homes,” the term refers to healthcare settings that facilitate partnership between consumers, their families, personal primary care physicians and practices, and specialists to coordinate and/or integrate services and supports.

Primary Care Case Management – Primary Care Case Management (PCCM) is based on the patient-centered medical home model. PCCM is built on delivering care through a team of providers and giving patients the tools and support they need to keep themselves healthy.

Re-balancing (tool 8) – This is a state option that awards the state with enhanced federal finance assistance for 12 months for each Medicaid enrollee transitioned from an institutional facility to a community setting.

Risk-based Managed Care (tool 13) – This is a fundamental shift in the way services and supports are financed and delivered.

Social Security Disability Insurance (tool 5) – Social Security Disability Insurance (SSDI) is given to almost all persons under age 65 with disabilities who are dually eligible for Medicaid and Medicare.

Substance Abuse and Mental Health Services Administration – The Substance Abuse and Mental Health Services Administration (SAMHSA) is a branch of the HHS charged with improving the quality and availability of prevention, treatment and rehabilitative services in order to reduce illness, death, disability and cost to society regarding substance abuse and mental illnesses. The Administrator of SAMHSA reports directly to the secretary of the HHS.

Supplemental Security Income (tool 5) – Defined in the Medicare Glossary, Supplemental Security Income (SSI) is a federal income supplement program funded by general tax revenues (not Social Security taxes). It is designed to help aged, blind and disabled people who have little or no income and provide cash to meet basic needs for food, clothing and shelter. People who receive SSI because of disability or because they are 65 years of age or older are automatically eligible for Medicaid in 39 states.

United States Department of Health and Human Services – HHS is the principal agency for protecting the health of all Americans. It is composed of the Office of the Secretary, which has 18 Staff Divisions, and 11 Operating Divisions.

Universal Design (tool 26) – Universal Design (UD) refers to broad-spectrum ideas meant to produce buildings, products and environments that are inherently accessible to both people with and without disabilities.

Voluntary Prescription Medications (tool 8) – Under Medicare Part D, a federal program to subsidize the costs of prescription drugs for Medicare beneficiaries in the United States, this term refers to the Medicare Part D benefit that pays for medicine for senior citizens and disabled Medicare patients who have signed up for separate drug-insurance plans through private insurers.