

Structuring New Service Delivery Models for Individuals with Intellectual and Developmental Disabilities

By Alice Lind and Nancy Archibald, Center for Health Care Strategies

REVISED
FEBRUARY 2013

The system of services and supports available to Medicaid beneficiaries with intellectual and developmental disabilities (I/DD) seems caught between the past and future. The old system of institutionally based care is rapidly being replaced by home- and community-based alternatives. At the same time, constraints and burdensome regulations limit the availability of supported housing for the I/DD population. Similarly, the old medical model of care is giving way to person-centered life plans reflecting the goals and strengths of people with I/DD. But, in a system still dominated by fee-for-service providers, there is no mechanism to coordinate and implement those plans.

New models of service delivery are needed within Medicaid to advance more integrated systems that deliver better value to beneficiaries. This brief from the Center for Health Care Strategies (CHCS) offers state Medicaid leaders a set of principles to guide innovative service delivery models, including recommended core structural elements. Examples of innovations provide guidance to states seeking new ways to support people with I/DD and their families. This brief draws from a CHCS small group consultation (see page 4 for a list of participants) in spring 2012 that convened state officials, providers, and consultants to identify opportunities for advancing integrated care for people with I/DD.

Current Systems of Service Delivery

The approximately 4.5 million people in the United States with I/DD have complex service needs that are met by a broad array of providers and settings.^{1,2,3,4} Prompted by litigation, the Olmstead decision, and the Americans with Disabilities Act, the service delivery system for people with I/DD has shifted in recent years to a home- and community-based services model.^{5,6} By 2006, 78 percent of long-term services and supports funding for persons with I/DD was spent on community-based services.⁷ While this shift represents a much-needed move toward deinstitutionalization, the subsequent proliferation of providers and programs has created challenges in terms of

IN BRIEF

The approximately 4.5 million people in the United States with intellectual and developmental disabilities (I/DD) have complex service needs that are met by a broad array of providers and settings. As the nation's long-term services and supports system shifts from institutionally-based care to home- and community-based alternatives and person-centered planning becomes increasingly important, services for individuals with I/DD need to be tailored accordingly. New models of service delivery need to focus on more integrated systems that deliver better value to these high-need beneficiaries.

This brief offers a set of principles to guide innovative service delivery models, including recommended core structural elements. Examples of innovations provide guidance to states seeking new ways to support people with I/DD and their families.

access to services, care coordination, quality oversight, and cost control.

Publicly-financed programs pay for many I/DD services. Medicaid provides the largest source of public funds, paying for 78 percent of I/DD services in 2005; an additional 14 percent came from state sources with the remaining eight percent from other federal sources such as Supplemental Security Income payments and the Social Services Block Grant.⁸ The vast majority of those funds are spent on a fee-for-service basis.

In the last 30 years states have moved about two-thirds of their Medicaid enrollees into managed care programs; however, this shift has generally not included people with disabilities because of their more complex needs, concerns about the adequacy of provider networks, and the inexperience of health plans in serving this population.⁹ Now though, states appear more willing to move populations

with complex needs, including the elderly and disabled, into managed care programs.¹⁰

Although Medicaid provides the majority of funds for I/DD services, Medicare is also a significant contributor. Approximately 20 to 30 percent of people with I/DD are dually eligible for Medicare and Medicaid.^{11,12,13} The lack of alignment in the services and funding provided by Medicare and Medicaid makes coordinating service delivery even more difficult for this group. As a result there is considerable policy interest in integrating Medicare- and Medicaid-covered services for dually-eligible people with I/DD.

States and the federal government, as the administrators of Medicaid and Medicare, are under pressure to address well-documented challenges in the current service delivery system. These include:

- Waiting lists for services;
- Limited access to quality care and services;
- Inadequate management of health conditions;
- Poor health outcomes; and
- Misaligned expenditures.^{14,15,16}

In addition, state and federal budget pressures compel policymakers to design more innovative and cost-effective systems of care for people with I/DD.

Guiding Principles for I/DD Service Improvements

Innovations in service delivery for people with I/DD should ideally be structured within a set of guiding principles that are consistent with national efforts, including the Developmental Disabilities Assistance and Bill of Rights Act¹⁷ and the American with Disabilities Act of 1990.¹⁸ To ensure high quality and person-centeredness, systems of service delivery must provide:

- **Access.** People with I/DD and their families must have access to the services and supports they need. Improvements must be made to better allocate resources and reduce waiting lists for services.
- **Choice.** People with I/DD and their families must have the ability to make decisions about their lives including where they live and who provides services to them.
- **Outcomes.** System structures should support people with I/DD and their families in achieving the outcomes they desire, including independence, fulfilling relationships, meaningful work, dignity, and well-being.

- **Integration.** Systems of service delivery must be integrated and coordinated to align programs and sources of funding.
- **Value.** Systems must demonstrate their value to consumers as well as purchasers of services. Comprehensive data collection and quality measurement are vital components of service delivery systems to help make the case for value.

Core Elements of New Service Delivery Models

Developing a shared vision for a new I/DD service model that adheres to the above guiding principles and responds to all key stakeholders will require significant effort. New models of service delivery should address the following core structural elements:

1. **Coordinated array of services and supports:** Integrating primary and acute medical care needs, behavioral health needs, and long-term services and supports, e.g., habilitation.
2. **Stakeholder engagement:** Incorporating the input of stakeholders in designing and managing these new models.
3. **Support networks:** Acknowledging individuals' support networks and incorporating those networks into life planning and resource allocation decisions. Models should adapt to changes in support networks over time, especially given the concern about aging caregivers as people with I/DD live longer.
4. **Existing provider infrastructure:** Incorporating a network design that includes critical providers, so that longstanding relationships between individuals with I/DD and their providers are not disrupted.
5. **Financial alignment:** Integrating available funding streams (Medicaid, Medicare, and state-funded services) and realigning incentives for improved quality. Savings generated should be reinvested to expand provider access and decrease waiting lists.
6. **Risk assessment and resource allocation:** Incorporating a standardized, comprehensive risk assessment for all individuals. Information from the assessment should be used to develop person-centered life plans that reflect the goals and strengths of people with I/DD and their circles of support. Periodic reassessments should guide – and adjust as necessary – resource allocation and the ratio of care managers to enrollees.

7. **Performance measurement:** Including measures of access, care coordination/transitions, member satisfaction, quality of life, and other key outcomes across a range of services and supports. To the extent permitted by federal regulations, performance data should be made available to the public.¹⁹
8. **IT infrastructure:** Using information technology to collect real-time data on risk assessments, service needs, and service utilization, and sharing it with providers and care managers as well as individuals with I/DD and their representatives. Information technology systems should also be capable of collecting data needed for performance measurement.
9. **Reimbursement rates:** Structuring reimbursement rates to encourage providers to serve more people with I/DD and spend adequate time to address often complex needs. Systems should transition away from fee-for-service payments toward payments based on episodes of care, risk-based arrangements, or pay-for-performance models. In addition, the capitation rate for long-term services and supports should be adequate to ensure access to the appropriate amount, duration, and scope of services.
10. **Life-long planning.** Acknowledging the life-long needs of persons with I/DD. Programs must provide stable and coordinated transitions from school to employment and facilitate movement to independent living arrangements. Models must address the changing needs for services as both people with I/DD and their caregivers age, including meeting the urgent need for residential services when caregivers become incapacitated.

New Models of Service Delivery

States and the federal government are thinking creatively about new models of service delivery for people with I/DD. Several innovative models that begin to incorporate the guiding principles and core elements detailed earlier include:

Medical and Health Homes

Patient-centered medical homes (PCMH) provide coordinated/integrated care through an ongoing relationship with a personal physician who encourages communication and uses information technology to improve patient access and outcomes.²⁰ States could contract with PCMHs to manage primary and acute care and behavioral health services and integrate that care with long-term services and supports from traditional I/DD providers. Through this

model, individuals with I/DD would be paired with a federally-qualified health center or other primary care practice that is certified as a PCMH and has an interdisciplinary team with experience in serving individuals with I/DD. The PCMH would be paid a monthly care management fee in addition to standard fee-for-service reimbursement.

New Jersey is preparing to implement such a model. The Department of Human Services, which includes both the Division of Developmental Disabilities and the state's Medicaid program, is working with four Medicaid managed care plans to develop pilot programs that will help Medicaid providers become PCMHs. Some of these providers will focus on serving people with I/DD. For example, the Arc Monmouth has provided both physical and behavioral health services in addition to long-term services and supports for over 20 years and will seek recognition from NCQA as a PCMH. Amerigroup New Jersey, one of the state's Medicaid managed care plans, will work with the Arc Monmouth to cover the costs of becoming a PCMH and track quality and outcomes data.²¹

Under the Patient Protection and Affordable Care Act (ACA), health homes were created to expand on the medical home model by including community and social supports and enhancing integration of physical and behavioral health care to meet the needs of individuals with multiple chronic conditions.²² Health homes provide services including comprehensive care management; care coordination and health promotion; comprehensive transitional care; individual and family support; referral to community and social support services; and the use of health information technology to link services. Health home providers represent a broader group than medical home providers and may include rural health clinics, community health or mental health centers, or other entities that would serve eligible people with I/DD.²³

Rhode Island has developed a health home state plan amendment for children with special health care needs. CEDARR Family Centers currently provide services including Comprehensive Evaluation, Diagnosis, Assessment, Referral, and Re-evaluation to a population of approximately 3,000 children and youth with special health care needs, including an estimated 30 percent who have I/DD. The four CEDARR centers already integrate services provided through the Medicaid managed care and fee-for-service systems as well as Rhode Island's local educational agencies and its child welfare system. They also oversee services provided through Rhode Island's home- and community-based waivers. As the CEDARR centers

transition to the health home model they will screen children for other conditions including obesity and depression; engage physicians in care planning and outcomes reporting; and enhance information sharing with Medicaid managed care plans.²⁴

Specialty Organizations/ACOs

In another model, states are contracting with specialized organizations such as accountable care organizations (ACOs) that will manage primary/acute care and behavioral health care services as well as traditional I/DD services. Under an ACO model, individuals with I/DD would be enrolled in a qualifying health system that includes providers with expertise serving persons with I/DD. Payment approaches for ACOs can be either fee-for-service with shared savings, partially capitated, or fully capitated.

New York State is developing entities called Developmental Disabilities Individual Support and Care Coordination Organizations (DISCOs). These nonprofit organizations will function as fiscal intermediaries and provide individualized supports and services in addition to care coordination to people with I/DD. DISCOs will provide supports and services directly or through sub-contracts with other providers.²⁵

Managed Care Entities

Traditional medically oriented managed care models have not been considered adequate to meet the broad needs of people with I/DD. However, **Arizona, Michigan, and Wisconsin** have included people with I/DD in their managed long-term services and supports programs. An evaluation of these programs found that they improved access to long-term services and supports, improved coordination of care, and enhanced beneficiaries' choice of providers.²⁶

In **Wisconsin**, the Family Care waiver uses Aging and Disability Resource Centers (ADRC) as the single point of access to a managed long-term services and supports system for people with physical disabilities, people with I/DD, and the frail elderly.²⁷ Flexible and coordinated services are provided through managed care organizations and individuals have a say in the services they receive. This program component entitled "Include, Respect, I Self Direct" (IRIS) uses a tool, the Long-Term Care Functional Screen, that is administered by ADRC staff to determine service needs and calculate the amount of money available for services.

Advocates criticized the use of the functional screen within managed care in Wisconsin because, in a small number of cases, individuals were eligible for a higher number of service hours than calculated by the screening tool. However, an independent review of the program found a high level of consistency between the results of the functional screen assessments and the functional eligibility criteria described in Wisconsin's administrative code²⁸ Use of the IRIS program has, in the vast majority of cases, given participants more choices, control, and freedom to design service plans that meet their needs, and the Department of Human services is working to fine-tune the assessment system.

Conclusion

As envisioned, these models represent a major departure from current delivery systems for people with I/DD. Each model has the potential to improve quality, resource allocation, integration of services, and cost-effectiveness. New models of service delivery should embrace the guiding principles and core elements described herein to move from outdated delivery systems care to more cost-effective delivery models focused on ensuring better access to person-centered, coordinated services and supports.

Small Group Consultation: Innovations in the Structure and Funding of Care for Medicaid Beneficiaries with Intellectual and Developmental Disabilities

On May 14, 2012, CHCS was joined by the below group of national experts to discuss opportunities to improve integrated care delivery for people with I/DD. Their ensuing discussion formed the basis for many of the recommendations discussed in this paper. We thank these experts for their expertise and ideas in advancing the state of the art in care delivery for those with I/DD.

STATES

Dawn Zekis, Director of Policy and Planning, Arkansas Medicaid

Judy Webb, Director, Division of Quality Management and Planning, Michigan Department of Community Health

Courtney Burke, Commissioner, Office for People with Developmental Disabilities, New York State

PROVIDERS

Jan Abelseth, PhD, Associate Executive Director, Nassau AHRC, New York

Judith Chamberlain, MD, Senior Medical Director, Aetna Medicaid

Beth Marootian, Director of Quality Management, Neighborhood Health Plan, Rhode Island

Joseph Stankaitis, MD, Chief Medical Officer, Monroe Plan for Medical Care, New York

CONSULTANTS

Allan Bergman, Independent Consultant

Gretchen Engquist, Burns and Associates

Brendan Hogan, Bailit Health Purchasing

Cyndy Johnson, CJ and Associates

William Johnson, CJ and Associates

Systems of Care Innovations for Individuals with Intellectual and Developmental Disabilities Series

This report is part of CHCS' *Innovations in Systems of Care for Individuals with Intellectual and Developmental Disabilities* series, which was developed to help state and other policymakers identify and implement systems of care that improve outcomes for individuals with intellectual and developmental disabilities, their families, and communities. The publications, supported by Schaller Anderson, an Aetna company, provide policy and technical resources to guide program identification and implementation. Other titles in this series, available at www.chcs.org, include:

- **Systems of Care for Individuals with Intellectual and Developmental Disabilities: A Survey of States** – Brief describes the results of a national survey of states regarding current delivery systems and planned innovations.
- **Trends and Challenges in Publicly-Financed Care for Individuals with Intellectual and Developmental Disabilities** – Resource paper summarizes important trends and challenges facing the publicly-funded service delivery system for people with I/DD.

About the Center for Health Care Strategies

The Center for Health Care Strategies (CHCS) is a nonprofit health policy resource center dedicated to improving health care access and quality for low-income Americans. CHCS works with state and federal agencies, health plans, providers, and consumer groups to develop innovative programs that better serve people with complex and high-cost health care needs. For more information, visit www.chcs.org.

Endnotes

- ¹ G. Krahn, L. Hammond and A. Turner. "A Cascade of Disparities: Health and Health Care Access for People with Intellectual Disabilities." *Mental Retardation and Developmental Disabilities Research Reviews*, 2006 12:70-82.
- ² Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities Health Surveillance Work Group. *U.S. Surveillance of Health of People with Intellectual Disabilities*. September 10-11, 2009.
- ³ Note that while there is overlap between developmental disabilities and intellectual disabilities, these conditions are not the same. Thus, an individual may have a developmental disability without being intellectually disabled or an intellectual disability without being developmentally disabled. The NHIS-D estimated that of the people meeting the criteria for either intellectual or developmental disability, 28 percent were both intellectually and developmentally disabled; 24.3 percent had an intellectual disability alone; and 47.7 percent had a developmental, but not intellectual disability. S. Larson, C. Lakin, L. Anderson, N. Kwak, J. Lee, and D. Anderson. "Prevalence of Mental Retardation and/or Developmental Disabilities: Analysis of the 1994/1995 NHIS-D." *MR/DD Data Brief*, 2000 2(1).
- ⁴ J. Crowley and M. O'Malley. *Profiles of Medicaid's High Cost Populations*. The Kaiser Commission on Medicaid and the Uninsured. December 2006.
- ⁵ D. Braddock. "Community Mental Health and Mental Retardation Services in the United States: A Comparative Study of Resource Allocation." *American Journal of Psychiatry*, 1992 149(2).
- ⁶ D. Braddock, R. Hemp, and M. Rizzolo. "State of the States in Developmental Disabilities 2004." *Mental Retardation*, 2004 42(5).
- ⁷ D. Braddock. Boston: Federal Reserve Bank of Boston. Proceedings from a Conference on Housing for People with Disabilities. Held on February 5, 2010.
- ⁸ The State of the States in Developmental Disabilities, 2005. Colman Institute, University of Colorado, 2005.
- ⁹ Kaiser Commission on Medicaid and the Uninsured. *People with Disabilities and Medicaid Managed Care: Key Issues to Consider*. February 2012. Publication #8278.
- ¹⁰ Ibid.
- ¹¹ The Arc. "Overview of Dual Eligibles." Available at <http://www.thearc.org/page.aspx?pid=3312>.
- ¹² E. Breslin Davidson and T. Dreyfus. "Dual Eligibles in Massachusetts: A Profile of Health Care Services and Spending for Non-Elderly Adults Enrolled in Both Medicare and Medicaid." Massachusetts Medicaid Policy Institute, September 2011. Available at: <http://www.massmedicaid.org/~media/MMPI/Files/MMPI%20Duals%20Chart%20Pack.pdf>.
- ¹³ D. Mancuso. "Characteristics of High-Risk Medicaid Enrollees and Dual Eligibles: Implications for Health Home Design and Care Management Strategies." Washington Department of Social and Health Services, February 2012. Available at: http://www.chcs.org/usr_doc/Presentation_Feb_1_2012.pdf.
- ¹⁴ G. Enquist, C. Johnson, and W. Johnson. *Trends and Challenges in Publicly-Financed Care for Individuals with Intellectual and Developmental Disabilities*. Center for Health Care Strategies, August 2012.
- ¹⁵ Centers for Disease Control and Prevention, op. cit.
- ¹⁶ Thornton, op. cit.
- ¹⁷ See <http://www.acf.hhs.gov/programs/add/ddact/DDACT2.html>.
- ¹⁸ See <http://www.ada.gov/pubs/ada.htm>.
- ¹⁹ United States Code of Federal Regulations 45 CFR 164, Subpart E – Privacy of Individually Identifiable Health Information. Available at: <http://www.hhs.gov/ocr/privacy/hipaa/administrative/privacyrule/index.html>.
- ²⁰ *Joint Principles of the Patient Centered Medical Home*. American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians and the American Osteopathic Association. February 2007. Available at: <http://www.pccpc.net/joint-principles>.
- ²¹ B. Fitzgerald. "Building a PCMH for the Developmentally Disabled." *NJSpotlight*, April 23, 2012. Available at: <http://www.njspotlight.com/stories/12/0422/2029/>.
- ²² "Health Homes for Enrollees with Chronic Conditions. State Medicaid Director Letter #10-024. Centers for Medicare and Medicaid Services. November 16, 2010. <https://www.cms.gov/smdl/downloads/SMD10024.pdf>
- ²³ *Health Homes: Opportunities for Medicaid*. Center for Health Care Strategies. March 2011. Available at: http://www.chcs.org/usr_doc/Health_Homes_Fact_Sheet.pdf.
- ²⁴ P. Choquette and Alison Croke. Rhode Island Health Home Initiative. Rhode Island Executive Office of Health and Human Services, February 2012. Available at: http://www.chcs.org/usr_doc/ICRC_HH_Slide_binder_March_2012.pdf.
- ²⁵ People First Waiver Glossary of Terms: Definitions of words and concepts related to the People First Waiver. New York State, Office of People with Developmental Disabilities. Available at: http://www.opwdd.ny.gov/sites/default/files/documents/people_first_glossary_of_terms.pdf.
- ²⁶ R. Gettings, "Reassessing the Impact of Managed Care in the Developmental Disabilities Sector," *The National Leadership Consortium on Developmental Disabilities*, 2009 1(1). Available at: [http://www.nasddds.org/pdf/PolicyInsightsBulletin\(March2009\).pdf](http://www.nasddds.org/pdf/PolicyInsightsBulletin(March2009).pdf).
- ²⁷ For more information, see <http://www.dhs.wisconsin.gov/bdds/iris/>.
- ²⁸ P. Stuber, E. Driliias, J. Fontaine, J. Martin, A. McGuire, M. Regan, et al. "An Evaluation of Family Care." Legislative Audit Bureau, April 2011. Available at: <http://legis.wisconsin.gov/lab/reports/11-5full.pdf>.