Making the Connection

Creating Health Care that Serves People with Disabilities

COMMUNITY CATALYST

BOSTON CENTER FOR INDEPENDENT LIVING

A Health Care System Designed to Serve Adults with Disabilities

Adults with disabilities on Medicare and/or Medicaid have been very poorly served in the existing health care delivery system. Most of all, recipients report care is fragmented and episodic, with little coordination between providers and settings of care. Additionally, a recent Health Affairs article reports that younger Medicare disabled beneficiaries experience significantly greater difficulty with cost and access than the non-disabled elderly. Good, proactive care and support can be provided within existing financial resources if the delivery system can be redesigned to integrated preventive, acute, and community-based care. The time is now for people with disabilities to be served by health care programs that integrate consumer-directed, community-based services and supports with a continuum of health care services ('Medicare Doesn't Work As Well For Younger, Disabled Beneficiaries As It Does For Older Enrollees', Juliette Cubanski and Patricia Neuman, HEALTH AFFAIRS 29, NO. 9 (2010).

Background

The Obama Administration has the opportunity through the new health care reform law (ACA) to drive significant redesign of the health care system. The new Center for Medicare and Medicaid Innovation (at CMS) is charged with designing and testing innovative ways of providing and paying for health care that have the potential to reduce costs while preserving or enhancing health care quality. The Federal Coordinated Health Care Office (CHCO) within CMS is charged with more effectively integrating policy and programs for those eligible for both Medicare and Medicaid (dual eligibles). Don Berwick, MD, CMS Administrator, and Henry Claypool, Administrator of the Office on Disabilities at HHS, and key policymakers at CMS are very aware of the need and opportunity to build delivery systems that are designed to serve people with disabilities.

For persons with disabilities, including dual eligibles and those eligible for Medicaid only, there is an unprecedented opportunity to advocate for new health systems that learn from and expand on proven clinical models that have earned consumer confidence. However, at this time of opportunity, states are facing unprecedented budget deficits driven in part by spiraling health care costs. In the absence of a proactive consumer voice, we risk that states will contain costs by limiting benefits and eligibility and/or by shifting costs to those who are most vulnerable and at risk. There is a limited window of time to be heard and to demonstrate that people with disabilities are the key to success in developing new models of care.

Community Catalyst and the Boston Center for Independent Living, in consultation with providers who have led proven clinical models, have come together to convene advocates to call on the Obama Administration to prioritize – and to involve the disability community in – creating new policies and systems of care. We have engaged Susan Kaufman (who has worked with public health care financing and primary care over the last 25 years) to provide project leadership; and Christopher Duff, former CEO of AXIS Healthcare, a disability care organization in Minnesota, to provide consultation in consumer engagement and demonstration design.

A Redesigned Delivery System

"They provide high-quality health care, they're the best! They go the extra step to provide preventative services, I don't wind up in hospitals, I get a wheelchair in a timely way that fits my very unique needs, they strongly support my personal assistance services."

Peter Cronis, institutionalized sixteen years, BCIL employee for 23 years and counting, speaking about Commonwealth Care Alliance

The principles for health care delivery systems described below are grounded in the experiences of persons with disabilities and their advocates, building upon the best practices of systems serving adults with disabilities on Medicaid and/or Medicare. These systems include the Commonwealth Care Alliance of Massachusetts, Independence Care System of New York City, AXIS Healthcare of Minnesota, and the Wisconsin Partnership. Our focus is provider-driven clinical models such as PACE for the elderly, but designed to serve adults with physical disabilities or multiple chronic conditions that rely on Medicaid and/or Medicare for their health care needs. While the focus is on adults with physical disabilities, this work will lay the groundwork for systems of care designed to meet the needs of adults with mental health and intellectual disabilities and children with special needs. The key themes are a focus on primary and preventive care, and integration of all care and services from acute to community-based supports.[1]

Principles for Integrated Care Systems

1. Consumer Direction is primary and includes:
   Personalized plans of care, incorporating individual health care goals and preferences, based upon a functional assessment.
   Care and Support Teams, directed by the consumer with involvement of family, clinicians and care givers.
   Dignity of Risk and Informed Decision-making, enabling and empowering consumers to develop, negotiate and implement plans to accept risk for and control of ADLs, IADLs, and health maintenance activities.
   Enhanced Independence, fostered by providing access to medically or functionally necessary DME (durable medical equipment) and AT (assistive technology).
   Consumer involvement in governance, to provide participant/advocate input into programmatic and governance policy and direction.

2. Service Delivery includes:
   Integrated services across all settings (hospitals, medical offices, and residential settings) and types of care and support (physicians, therapists, paraprofessionals, family and informal caregivers).
   Redesigned primary care including multidisciplinary teams with shared decision making, enhanced capabilities for comprehensive assessments, home episodic care responses, and integrating DME, behavioral health therapy services.
   Access to experienced providers, with training and interest in serving persons with disabilities.
   24/7 availability of informed and knowledgeable clinicians, with access based on immediacy of need.
   Early intervention strategies (consumer education and training, clinical practice guidelines) to prevent complication or exacerbation of chronic conditions.
   Safeguards to eliminate institutional bias in the functional or financial eligibility criteria for long-term services and supports and allowing consumers choice of setting and provider of care.

3. Coordination includes:
   Coordination of decision-making across settings of care and support, including work and social activities.
   Identified coordinator of care, experienced with adults with disabilities and in managing care across settings and in the community.
   Consumer option to: 1) hire independent coordinator; 2) serve as their own coordinator; or 3) identify a family member or involved friend to coordinate care.

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[1]This document incorporates principles delineated in two papers: "Guiding Principles for Services Individuals with disabilities through Medicaid Health Plans" by AHIP (American Health Insurance Plans) and ADAPT (2007); and "Principles of Managed Care for People with Physical Disabilities" by MnCCD (Minnesota Consortium of Citizen with Disabilities) and AXIS (2003).

Integrated, comprehensive health care and support records accessible to and managed by the consumer and care coordinator, along with key involved professional and para-professional caregivers.
Expedited complaint resolution, as well as independent advocacy and appeal processes to address consumer needs and concerns.

4. Financing includes:
Payment support for a single plan of care, enabling flexible utilization of health, social and community-based care resources, not artificially divided between acute and long-term care.
Adequate funding directed to primary care and care coordination.
Risk-adjusted financing to reflect and adequately support the high level of medical complexity and community supports required by the enrolled consumers.
Investment of resources with the goal of maintaining or improving quality of life.
Maximized financial resources dedicated to direct services, minimizing administrative costs.

About Community Catalyst

Community Catalyst is a national non-profit advocacy organization dedicated to quality affordable health care for all. Since 1997, Community Catalyst has been working to build the consumer and community leadership required to transform the American health system. With the belief that this transformation will happen when consumers are fully engaged and have an organized voice, Community Catalyst works in partnership with national, state and local consumer organizations, policymakers, and foundations, providing leadership and support to change the health care system so it serves everyone - especially vulnerable members of society. Community Catalyst believes a strong consumer voice will help advance public policies that promote high-quality, comprehensive, coordinated care that works well for consumers and also makes public programs sustainable over the long term.

About Boston Center for Independent Living

BCIL has provided advocacy and mentoring services for people with disabilities since its founding in 1974, when it became the second independent living center in the country. The organization seeks the full integration of people with disabilities into society by empowering individuals to take control over their lives and become active members of their communities. BCIL's systemic advocacy efforts have produce compliance with the ADA by medical facilities; expansion of consumer-directed personal care assistance; and growth in Medicaid buy-in coverage (CommonHealth) for people with disabilities.