



National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

February 7, 2012

Acting Administrator Marilyn Tavenner
Center for Medicaid and Medicare Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244

Dear Administrator Tavenner:

The National Council on Disability recognizes the need to reform health care and life-long services and supports delivered through Medicare and Medicaid programs to all citizens, including those with disabilities. Although the pathway to change varies with each jurisdiction, many states and the federal government are working to restructure systems to address long standing problems for people with disabilities regarding access to health care and community supports while controlling service related costs through new management strategies collectively referred to as managed care.

NCD issues this correspondence to (a) articulate the implications of managed care arrangements in publically financed service systems for individuals with disabilities, and (b) offer recommendations to address these issues. The intent of this letter is to strengthen reform efforts with the result that people with disabilities will be better for them.

The Issues:

Change happens in the context of current reality. Any system transformation must begin with a full assessment of the current environment in order to identify the opportunities and strengths to build on as well the weaknesses and risks that must be mitigated.

Rapid Development. The pressure to control costs is propelling states to propose the adoption of Medicaid managed care systems at a pace that has been characterized as a “state stampede.” Many of these proposals encompass both acute and long-term services and supports, are targeted to both elderly and non-elderly persons, include people with and without disabilities and address care for persons dually eligible for both Medicaid and Medicare. Eleven states currently operate capitated Medicaid long-term service and support programs (KKF, October 2011a). A recent nationwide survey revealed that an additional 27 of 43 responding states planned to expand existing managed care programs or establish new capitated managed care systems to cover Medicaid recipients of long-term services and supports (HMA/KCMU, September 2011).



Furthermore, under the State Demonstrations to Integrate Care for Dual Eligible Individuals, CMS has awarded planning grants to fifteen states across the country to design new approaches to better coordinate care for individuals dually eligible for Medicare and Medicaid with the goal of identifying and validating delivery system and payment coordination models that can be tested and replicated in other states. CMS is also making technical assistance available to all states interested in improving services for dual eligible individuals.

State Managerial Capacity. The rapid development of managed care programs is occurring at a time when hard-pressed state agencies have incentivized early retirements and reduced personnel as part of broader budget balancing plans. As a result, the knowledge base and experience levels of state agencies have been seriously eroded and fewer administrative and technical personnel are available to develop and administer a managed long term care programs for people with disabilities. Moreover, the reservoir of experience in operating managed long-term support systems is much shallower than it is in the health care arena – both within state governments and among managed care organizations. In some states, Medicaid agencies are for the first time taking the lead in planning and developing programs for people with disabilities who, prior to managed care, received services in systems operated by non-Medicaid disability agencies. With limited knowledge, experience and staff resources, the capacity of state agencies to not only hold managed care contractors accountable, but also to ensure the health and safety of program participants, and evaluate quality, and make improvements in the management and delivery of services over time is likely to be severely restricted.

Health, Safety and Quality. Abuse, neglect, exploitation, the use of mechanical and chemical restraints, unexplained injuries and denial of services are far too prevalent in our current long-term system of services. CMS has made significant strides in holding states accountable for addressing health and safety issues in the 1915(c) Medicaid Home and Community Based Waiver program; but requirements governing program design, state monitoring and reporting to CMS have not been mandated for managed care programs approved under Section 1115 demonstration waivers or under the dual eligible pilot demonstrations.

Performance Measurement. The Balanced Budget Act of 1997 and subsequent federal regulations have established expectations for ongoing quality assessment and performance improvement programs. Unfortunately, the tools most commonly used for monitoring quality in Medicaid managed care (External quality review organizations (EQROs), Healthcare Effectiveness Data and Information Set (HEDIS), Consumer Assessment of Healthcare Providers and Systems (CAHPS), Accreditation, and Pay for performance) are primarily focused on acute care and are not relevant to the provision of long term supports and services for people with disabilities.

Published performance standards, requirements or terms and conditions specific to long term supports and services for non-elderly people with disabilities are similarly absent in



Section 1115 demonstration waivers and in requirements for pilot projects funded under the Medicaid-Medicare dual eligible program. Moreover, neither of these programs mandate standard reporting requirements or relevant performance outcomes measures. The National Quality Forum is the entity with the lead responsibility for endorsing health care quality measures - that is, determining the measures that should be recognized as national standards. Among the more than 1,500 measures approved to date, only a handful are even minimally related to disability services - basically those related to behavioral health and early childhood development.

Determining Cost-Effective Use of Resources. Capitated payment rates are central to improving the cost-effectiveness of services within a managed care environment because they allow the managing entity, the managed care organization or “MCO” wide latitude in utilizing available dollars to design interventions that both save money and improve outcomes. States have extensive experience in calculating managed care rates for health care services because they have access to well-researched assessment instruments and extensive cost data from both the public and private sectors. In contrast, in MMLTSS programs the assessment instruments currently in use vary from state-to-state and from target population to target population. Frequently, the psychometric properties of such instruments are not well-documented. In addition, in the long-term supports arena, states generally have limited encounter data upon which to predict the cost consequences of alternative intervention strategies. The use of invalid and unreliable assessment data in calculating capitation rates can destabilize the finances of a managed care system and place enrollees at grave risk of receiving inadequate and inappropriate services and supports.

In case of Medicaid recipients who require acute and long-term supports, the potential for achieving savings lies disproportionately in the area of long-term services and supports. In FY 2007, long-term support expenditures on behalf adults with disabilities (ages 19-64) requiring LTSS averaged 72 percent of their total Medicaid service costs (KKF, October 2011b). It is important, therefore, that a state use valid and reliable instruments and data in calculating LTSS capitation rates and have trained personnel to administer and interpret the results. These are factors which CMS should take in account in determining a state’s readiness to enroll its Medicaid disability population (or portions thereof) in managed long-term support plans.

With respect to people with life-long disabilities who will need services for decades, it is important to think in the very long term when determining whether services are cost effective. Cost savings in long-term services and supports may be realized outside the life cycle of a managed care contract. For instance, attention to supports for family care givers to reduce the stress of care-giving increases the likelihood that families will be able to continue to provide support over extended periods of time, even multiple decades. Upfront investment in employment services may not result in more independence during the contract period but can significantly reduce the need for public resources for many decades into the future. Person-centered services includes an aspect of planning beyond the here and now with an eye to the future.



Institutional Service Carve-Outs. While managed care offers potential for reducing the institutional bias of Medicaid policy, a number of state managed LTSS proposals (.e.g. New York, North Carolina) are carving institutional services out of the managed care program. This action makes it impossible for states to lower costs by substituting equally effective but less expensive community services for institutional care. Taking the most expensive support alternative out of the cost calculation not only will decrease any savings that might otherwise occur, but also will provide the option for managed care programs to divert high cost individuals to institutional services, thus increasing the numbers serviced in the most costly support option. The net effect would be contrary to the spirit of if not a full contradiction of the Americans with Disabilities Act (ADA) as interpreted by the U.S. Supreme Court in its 1999 Olmstead decision. Moreover, for states that presently expend a substantial portion of their Medicaid LTSS budgets on institutional services, such proposals remove what is perhaps the most significant opportunity to achieve system-wide savings and improve participant outcomes. If resources are to be managed effectively to ensure that everyone receives services, including those still on waiting lists, all resources must be managed under the same program umbrella.

Overarching Program Goals. For the most part, discussions regarding the expected benefits of state managed care proposals are limited to “reducing costs” and “coordinating care.” For people with disabilities, coordinating care should be viewed as a means toward an end, not an end in itself. Many of the state managed care proposals we have reviewed to date place too little attention on the outcomes being sought for people receiving services, such as a better quality of life, control over their services and supports, full participation in community life, protection of individual rights, employment options for working age adults, etc. In addition to making services more cost-effective, the aim of such systemic transformations should be to help people with disabilities live better, richer lives and gain access to the opportunities promised by the ADA.

Collaboration Among Public Partners: Opportunities for Individuals with disabilities to live and participate in community life are made possible by multiple public programs other than Medicare and Medicaid including vocational rehabilitation, public education, public housing, work force investment boards and Centers for Independent Living. Coordination between these public systems and Medicare and Medicaid systems are critical to successful outcomes. Many times individuals are transitioning between these public systems and coordination is essential. This is particularly true for all young adults leaving public education. Collaboration between public education and adult service systems at the system level, not just the individual level, is necessary to ensure that young adults in transition do not languish, losing skills learned in school and compromising their opportunities for employment as adults. Collaboration between Medicaid and Vocational Rehabilitation are important to ensure that employment goals are supported by long term supports and services.



Recommendations

CMS Approval of State Applications. Prior to approving a state application to implement a managed care program, CMS must conduct a state readiness assessment to determine whether the submitting state has in place the resources and capacity necessary to effectively administer and oversee the proposed managed care program, and to hold managed care entities accountable for their performance. The readiness assessment must include a review of the state's plan and operational capacity as well as the requirements set out in the contracts between the state and the managed care entities.

State Operations and Readiness. The readiness assessment forms the basis for CMS' terms and conditions of approval of a state's managed care plan. The assessment should include a thorough examination of the following core elements of the state's managed care implementation plan, with the findings and conclusions from this assessment included in the state's waiver/demonstration application:

- The involvement of disability stakeholders in the development of the state's managed care plan and the ongoing roles stakeholders will play in assessing the timeliness and effectiveness of services.
- The provision of services to all eligible individuals without the establishment of waiting lists.
- The inclusion of all Medicaid state plan services in the managed care option, including both community-based and facility-based programs that support people with disabilities in segregated environments to facilitate the transition from institutional to community services.
- The number, qualifications and disability-related experience of state personnel (including contract staff) who will be assigned to managing and overseeing the proposed managed care system, rectifying issues as they arise and continually improving system-wide management practices.
- The state's plan for implementing its proposed managed care system, including the schedule for phasing in services geographically and by population groupings.
- The state's proposed system for monitoring feedback from program participants through a complaint system, hotlines, consumer surveys and outreach sessions with system stakeholders (participants, providers, professional associations and advocacy groups).



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- The performance benchmarks to be used in measuring access to services, ADA compliance, and participant health and safety.
- The state's information gathering and reporting plans, including a description of the data management and reporting capacity of the state, participating MCOs and other service providers. The state's plan must ensure access to adequate and timely data, plus the capacity to analyze such data in order to identify, determine and evaluate: (a) service patterns or trends, (b) provider performance, (c) the extent to which participants receive the services and supports they need, and (d) the adequacy and responsiveness of existing provider networks. States' data management capacities must additionally address provisions regarding the gathering and assessment of data related to key participant outcomes including: (a) the extent to which participant rights are being protected, (b) the ability of participants to exercise choices, to be healthy and safe, and have ample opportunities to participate in employment and community life.
- The State's plans to evaluate its proposed managed care program and make publicly available the results of such evaluations and related summary statistical analyses and reports to CMS and the general public through annual performance reports, system or provider report cards, and other documents.
- The adequacy of the state's existing home and community-based service network to address the needs of all segments of the disability population including those with the most significant disabilities, to prevent institutionalization, and minimize the number of Medicaid beneficiaries with disabilities who receive round-the-clock institutional care.
- The existence (or lack thereof) of valid and reliable instruments to assess the service/support needs of eligible individuals with disabilities and predict the resources likely to be required to address those needs.
- The availability of community housing to meet the varied needs of individuals with disabilities who are transitioning from institutions to the community or being diverted from institutional placements.
- The adequacy of plan provisions aimed at guaranteeing participants a choice among two or more managed care plans as well as the information and supports necessary to make an informed decision regarding plan selection.



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- The state's plans to educate managed care enrollees and ensure they receive timely and complete information about obtaining services and responses to any questions they may have. In addition, managed care plan enrollees should have a mechanism for contacting the state directly when they have questions or concerns.
- The adequacy of provisions designed to safeguard the rights of program participants with disabilities, including the right to appeal plan and service related decisions.
- The adequacy of plan provisions to ensure the safe and effective transition of existing Medicaid beneficiaries to the state's planned managed health and/or long-term support program.
- The plan to coordinate policy and collaboration at the state level between Medicaid/Medicare and other publically financed services including public education, vocational rehabilitation, work force investment boards public housing and Centers for Independent Living at the state level.

Managed Care Contracts: CMS must review and approve state contracts with managed care entities prior to the enrollment of participants. This review should ensure that: (a) participants will have access to high quality services; (b) services for all individuals will be fully integrated in the community regardless of the significance of a person's disability; (c) participant rights, health and safety will be protected; (d) participants will be afforded the option of self-directing their services and of receiving the supports they need to do so, and; (d) the managed care organization contract, as well as provider sub-contracts, will adhere to all ADA requirements.

Managed care contract provisions must include:

- Person-centered practices in: planning that includes both an immediate needs and a long term view, service delivery, risk assessment and mitigation to ensure safety without compromising the participant's autonomy, service plan monitoring to ensure supports are adequate to meet the person's needs and are delivered as planned.
- Service coordination to ensure the seamless integration of supports across providers and evidence that service coordinators are trained and supervised in person-centered practices and service delivery.



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- A full description of services including supports offered to families as well as participants. The description should include provider qualifications and the processes to ensure that providers are and remain qualified, the use of criminal history checks, and the establishment, maintenance and use of abuse registries.
- A clear delineation of service plan approval standards and processes.
- Participant grievance and appeal processes.
- Consumer choice among qualified providers and the option to self-direct services regardless of the severity of one's disability.
- A description of the process for determining and implementing individual budgets and the supports available to individuals who direct their own services.
- Policies on the use and reduction of mechanical and chemical restraints; a system of reporting and investigating critical incidences such as abuse, neglect, exploitation, injuries, the use of restraints; policies in the administration of medication including self-administered medication.
- An ongoing quality assessment and performance improvement program to measure and monitor service access and quality and report outcomes to the state on a prescribed schedule. The quality management plan should include a description of discovery and remediation activities and the process for identifying quality improvement projects.
- Specifications for the development and implementation of state corrective action plans used to remediate issues or problems that are identified with plan performance.
- A requirement to execute interagency operating agreements with local public services systems such as public education, vocational rehabilitation, work force investment boards, public housing and Centers for Independent Living.

CMS Oversight:

While federal statutes and regulations have established expectations for ongoing quality assessment and performance improvement programs in managed care settings, the tools most commonly used for monitoring quality in Medicaid managed care are primarily focused on acute care and are not relevant to the provision of long term



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supports and services for people with disabilities. CMS must establish a process for ensuring that measurement tools that are normed on the various sub-populations enrolled in managed care programs encompassing long-term services and supports that can be employed by states to monitor performance. For example, for the I/DD population, the National Core Indicators is a nationally recognized tool for monitoring quality of long-term services and supports. Performance indicators should address key domains such as individual outcomes (employment, access to and participation in community life, contact with friends and family): participant rights; and family outcomes.

CMS should require states to commission an independent evaluation of their managed care programs and make the submission of the findings and conclusions growing out of this evaluation a condition of a state's renewal request.

In closing, we reiterate that the Council fully appreciates the need to reform health care and life-long services and supports delivered through Medicare and Medicaid programs to all citizens, including those with disabilities. The role of state agencies is the lynchpin to success. The effectiveness of states in involving stakeholders in the design of the program, executing contracts with managed care organizations that communicate clear expectations and reporting requirements, making the program transparent through public reporting, and holding contractors accountable through contract monitoring and enforcement are the critical elements to improving services while managing costs.

CMS must clearly communicate expectations, provide guidance and enforce requirements. Stakeholders at the state level must participate at the design stage and on an ongoing basis, review information made available about the performance of the managed care program.

The National Council on Disability will continue to contribute to the dialogue through the provision of information and on-going guidance to public agencies, people with disabilities and all stakeholders.

Sincerely,

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Chairman

CC:

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National Council on Disability

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