The National Disability Leadership Alliance

PRINCIPLES FOR PROVIDING COORDINATED QUALITY HEALTH CARE IN MEDICAID MANAGED CARE PROGRAMS FOR THOSE LIVING WITH SIGNIFICANT DISABILITIES

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The ***National Disability Leadership Alliance*** (NDLA) is a coalition of 14 leading national disability organizations led by individuals living with significant disabilities themselves and supported by grassroots constituencies living with disabilities in all states and the District of Columbia. The Alliance prides itself on serving as an authentic voice for those with disabilities and recognizes that states are moving rapidly into the arena of creating managed care programs that will address financing and delivery of services to beneficiaries living with serious disabilities and multiple chronic conditions, long excluded from managed care approaches due to the challenges of applying such methods to these high-risk patients and integrating services for physical health, behavioral health, developmental/intellectual disability, and long-term service and supports. The federal government is examining managed care approaches with states in demonstration projects being applied to those dually eligible for both Medicare and Medicaid who account for only 15% of Medicaid enrollees but about 40% of all Medicaid spending. This population includes 3.5 million beneficiaries with disabilities under the age of 65.

The ***National Disability Leadership Alliance*** has developed the following principles and urges that they be applied fully by both the Centers for Medicare and Medicaid Services (CMS) and individual state Medicaid programs as they examine ways to broaden the application of managed care to beneficiaries with significant disabilities in the interest of containing spiraling health care costs. These principles are not intended to oppose such managed care applications. They are offered in an effort to ensure that such managed care pursuits achieve their intended goals by being fair and deliberate, i.e., gaining experience and knowledge in stages, while guaranteeing necessary patient protections, care delivery features, performance and quality requisites and emphasis on community integration. With attention to these principles, we believe federal and state governments will be provided their best chance of achieving lower costs while improving the coordination, continuity and quality of care.

As CMS and state Medicaid programs grapple with how best to apply managed care to our higher risk, higher cost population, the Alliance hopes this set of principles will provide utility to these payers, as well as to beneficiaries, their advocates and other stakeholders who must be actively involved in all aspects of program development, evaluation, refinement and innovation. Such stakeholder engagement will help to ensure that beneficiaries will continue to receive necessary services and supports while reinforcing their capacity to work and enjoy productive, quality lives in their communities.

PRINCIPLE	DESCRIPTION
1. Emphasize Patient Individual Choice, Person-Centered Planning and Self-Directed Care and Services	Medicaid managed care affecting those with significant disabilities should be based on patient individual choice, person-centered planning and self-directed care and services. Beneficiaries in managed care must have choice in selecting service and support options, providers and care settings, especially in relation to the very personal nature of long-term care needs. Person-centered planning is designed to increase beneficiaries' self-determination, independence and inclusion in their communities. Self-direction emphasizes personal budgeting and oversight of one's direct services and supports related to life's instrumental functions, including activities of daily living, health maintenance, community participation and employment. Medicaid self-directed care programs have well demonstrated the capacity of beneficiaries to plan, direct and make appropriate and cost-effective choices about their care that improve their health, functionality and general well-being. This important element of quality care for those with disabilities should not be sacrificed in a managed care construct. At least for the initial three years of a Medicaid managed care program's implementation for such higher risk populations, when refinements can be made to address problem areas, Medicaid enrollees living with disabilities should be given the opportunity to actively opt into or out of these programs depending on the specific state program approaches offered. This trial period also would provide states with the opportunity to experiment with a few different Medicaid managed care plans simultaneously. After this initial three-year test period, managed care would become mandatory for all beneficiaries for whom the state then deems the approach appropriate. The state could then also offer two or more managed care plan options from which beneficiaries would choose.
2. Assess State Program Preparedness and Ensure Adequate Staged Transition to Full Implementation	Each state should evaluate its Medicaid managed care expansion preparedness and determine an implementation plan that phases in programs. States should undertake demonstrations projects that target specific sub-populations across differing disabilities and age groups initially to ensure program functionality and then make needed refinements that best align plan and program components before broader scale applications are undertaken. Experience is limited in managed care for higher risk disability populations, so states should not rush to full managed care program implementation which could result in widespread disruptions and negative health outcomes. It will require 2-3 years of experience to ensure that appropriate quality and performance features are in place and adequate payment rates set. As responsible financing partners to the states, CMS should review and approve such projects, as well as all incremental changes that states make in their Medicaid managed care program.
3. Ensure Strong Federal and State Oversight of Managed Care Program Impacts	Movement to managed care for broader Medicaid populations that are significantly disabled and experiencing multiple chronic conditions demands strong state/federal administration and oversight by qualified governmental officials. These officials should possess experience in addressing disability and chronic care needs, seek routine input from relevant stakeholders, appreciate the importance of establishing an explicit contract with managed care entities and ensure ongoing monitoring of performance against contract requirements. In partnership, both CMS and the state Medicaid programs must oversee program accountability and contract fulfillment.
4. Due Process and Appeals	The Medicaid Appeal/Fair Hearing process should apply and provide adequate due process and grievance and appeals mechanisms, spelling out such things as adequate notices, training and education opportunities sensitive to recipient learning levels and needs, enrollment rights and options, plan rules and benefits, etc. The enrollee process for appeals of coverage denials must be accessible, timely and operated by independent third-parties. Additionally, independent ombudsmen should be available to help beneficiaries deal with problems within the managed care plan.

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5. Establish Fair and Adequate Payment Rates and Reinvest Savings in Medicaid Services	States must ensure transparency in their rate setting and demonstrate that these rates are actuarially sound. In any managed care payment process intent on meeting the needs of those with significant disabilities, such payment rates must account for severity of condition and be adjusted for varying levels of risk. To accommodate this need, a "risk pool" or "risk corridors" approach can be taken. The former would provide a pool of funds that would be drawn from and added to the capitation payment to meet outstanding unpaid claims. The latter would create specially designed pools that would adjust payment based on estimated services and supports used by enrollees based on their disability severity and related demographics. Payment rates should initially be based on at least 2-3 years of the most recent Medicaid (and, as appropriate Medicare) claims data so payments account adequately for marketplace realities and are not artificially decreased to achieve savings. Therefore, state Medicaid budgets should not be cut prematurely on the basis of "anticipated" savings. Experience applied to higher risk populations under such programs is first needed before savings can be determined as definitive. Moreover, savings that are achieved should remain at the disposal of the state's Medicaid program and reinvested in needed services and supports and improved care access, quality, coordination and efficiency. Prescription drug costs should not be included in the managed care payment rate as their expense could in many instances severely undermine the financing needed for other essential benefits needed by higher risk beneficiaries. Medicaid coverage for prescription drugs must be robust and efforts to constrain these costs should be treated separately from the managed care construct as they have the potential to absorb too much of a fixed per beneficiary payment limit and seriously deprive funding for and access to other critically needed services.
6. Emphasize Primacy of Home- and Community-Based Services and Supports	Managed care is intended not only to achieve greater coordination of services in response to medical necessity but also improved efficiencies and lower expense without undermining quality care. In the context of long-term care, therefore, both community-based and institutional care must be included in these managed care efforts to determine where quality care can best be provided while achieving cost savings. Institutional services must not be carved out of state managed long-term services and support plans if lower costs and improved outcomes are serious goals. Home- and community-based services and supports are now included as an "optional" Medicaid benefit. These services must be given primacy if managed care is to be fairly applied to those with serious disabilities and achieve intended results. This may require the development of a single "blended payment rate" for long-term services and supports whether this care is provided in the home, the community, nursing homes, state centers or ICF-MRs. The role of discharge planning from hospitals is critical and discharge planners must be educated on all community service options so that community integration is promoted. Such an approach averts unnecessary obstacles to effective, lower cost community-based services that the majority of beneficiaries routinely cite as their preferred care setting and that current law demands. This and other payment-related incentives and penalties to reduce admission rates to higher cost long-term care institutions should be built into the state's contract with managed care entities. Managed care entities should provide a transition out program for beneficiaries already in nursing homes or other long-term care facilities. The payment rate should include a transition adjustment to ensure those in institutions receive start-up community-based services support. Manage care contracts should require the managed care entity to enter into agreements with hospitals to ensure that beneficiaries with disabilities are given a range of post-acute and long-term care options and are not forced into nursing homes.

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7. Ensure Stakeholder Participation in All Aspects of Planning, Refining and Updating Plan and Policy Development	Stakeholders – beneficiaries, family members, disability advocates, appropriate experts, support agency representatives and others as appropriate -- should be provided reasonable and timely opportunities to actively participate in the design, implementation and monitoring of managed care programs and the promotion of innovation that will improve coordination and quality of managed care as applied to beneficiaries with significant disabilities and multiple chronic conditions. Such stakeholder engagement should include input into any Section 1115 waiver development and implementation. Transparency in program development and operations is essential, as is assuring that clear, understandable descriptive information is available to beneficiaries about plan choices and their provisions. The managed care program's governance structure should include consumer presence and participation in policy-making decisions. The governance body should provide mechanisms for continuous stakeholder feedback to both government overseers and managed care entities on such matters of quality of care, contract compliance, consumer satisfaction, continuing program refinements and potential for innovation.
8. Require Managed Care Contract Specificity of All Expectations	Medicaid state directors must ensure that contracts with managed care entities that will serve beneficiaries with significant disabilities are transparent and contain explicit language spelling out clearly and comprehensibly the expectations for risk sharing between the state and managed care organizations. The agreement should, among other things, specify: (1) The managed care entity's reserves. (2) Its demonstrated understanding of state-specific Medicaid LTSS programs and evidence-based best practices related to those with disabilities of all ages. (3) Adequate quality controls, customer satisfaction assurances and measurable results documentation based on well-defined, published performance measures and metrics. (4) The requirements for delivery on the full range of services and supports to which Medicaid beneficiaries are entitled within the state's program. (5) Restrictions that prevent the managed care entity from financially benefiting from institutionalization of beneficiaries. (6) Ways to measure how provided services advance community integration. State managed care contracts should support and reward innovation that achieves compliance and improves upon best practices.
9. Ensure Consumer Protections and Non-Discrimination	Medicaid managed care programs addressing populations with significant disabilities must proactively ensure non-discriminatory care in settings that comply with federal and state laws, including the American with Disabilities Act (ADA), Rehabilitation Act and the Supreme Court's Olmstead decision requirements for reasonable accommodation, accessibility(physical, cognitive and sensory), community integration and communication sensitive to the individual preferences and needs of beneficiaries. The highest priority must be given to services that keep people out of institutions, including nursing homes. States must also provide consumers with protections that ensure the safety and security of patients without compromising their civil rights and dignity. Additionally, there must be protections to ensure network adequacy, cultural and linguistic competence, stakeholder input, strong oversight and enforcement mechanisms, and the continual collection and development of real time and beneficiary-oriented data measures that track successful health outcomes and the maintenance of independent living in the community.

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10. Institute a Sound and Accountable Consumer – Driven Quality Management and Improvement System	State Medicaid programs must oversee and ensure that managed care programs provide a quality management process that includes independent third-party monitoring, written evaluation of the managed care entities performance and assessment of various quality care indicators. These parameters need to be measured specific to the needs of persons with disabilities and should be based on the principles in this document. More specifically, a state's Medicaid management care quality assurance system must have capabilities (e.g., qualified personnel, information technology, analytical capabilities and more) for continuous quality monitoring, data collection and management, incident patterns and trends assessment , tracking across defined metrics (health- and function-related), periodic reporting of results and the ability to capture and assess feedback from beneficiaries and family members on customer satisfaction. Data collection should also include "Community Integration Performance Indicators," capturing the number of nursing home or other institutional placements, consumer directed programs, integrated housing, etc. The information technology system should be designed and implemented prior to implementation of the payment system and define the data elements required of the managed care entity, the provider network and the real-time incident reporting mechanism, while also ensuring adequate safeguards to protect confidentiality.
11. Ensure Comprehensive Range of Services and Supports Across the Health Care Continuum and Lifespan	Expanded managed care application to those living with significant disabilities should ensure coordination and continuity of care across the health care continuum. Medicaid managed care programs must also ensure that the needs of beneficiaries living with disabilities are adequately addressed across the lifespan and are responsive to medical and functional necessity. Face-to-face coordination of services on a voluntary basis should be an element of managed care. These services should be at least at the coverage levels currently in place. This means assurance of: a full range of acute and long-term care services and supports; peer support and mental health recovery models of service; personal care assistance; durable medical equipment and supplies; assistive technologies and more. The provision of such services should not be subject to arbitrary limitations or premature terminations divorced from considerations of medical necessity, nor should access to these services be subject to excessive waiting periods.
12. Ensure Adequacy of Provider Networks and Coordination between Providers	Medicaid managed care programs addressing the needs of those with significant disabilities and multiple chronic conditions must ensure adequacy of provider networks, including primary care physicians, specialists, sub-specialists, non-physician providers (e.g., rehabilitation therapists), skilled nursing and personal care assistance workers or attendants. Plans must ensure inter-communication and record-sharing between such providers to reduce duplication of effort and costs and promote optimal care continuity and coordination. Attendant recruitment, fair compensation and retention must be supported by managed care, as consistency of attendant services helps to avert costly secondary medical conditions. Where such providers are not within a reasonable travel distance of beneficiaries, travel to these physicians should be subsidized by the plans. To the extent possible, a beneficiary's continuing access to current providers should not be disrupted by movement to a managed care financing and delivery model, as long as these providers are willing to abide by the managed care plan rules and payment schedules.

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13. Ensure Access to Durable Medical Equipment and Supplies and Assistive Technologies	Managed care systems addressing the needs of those with significant disabilities must ensure adequate access to appropriate durable medical equipment, prosthetics, orthotics, supplies and assistive technologies that allow daily function and the capacity for independence and employment where feasible. Covered services should include professional assessments of beneficiaries' needs for such technology, as well as set-up, maintenance and user training. Managed care should also remain open to innovations in technologies that have the capacity to improve care quality and achieve short- and long-term cost savings.
14. Promote Community Integration by Utilizing Local Disability Service Networks	Medicaid managed care programs should promote community integration and transition to community-based services. We encourage utilizing existing community disability networks as components of the managed care delivery system. These agencies have served a critical role in many states in fostering beneficiaries' independence and capacity to live productive, quality lives. Moreover, many of these community service components are led by those with disabilities themselves and offer true models for person-centered planning, self-directed services and independent living. These organizations can play an integral role as the bridge between the acute care and the LTSS systems.
15. Support Informal/Family Caregivers	Managed care program addressing the needs of those with significant disabilities must be responsive to the needs for respite and other supports for family and other informal caregivers who are a critical component to ensuring care continuity and coordination as well as reduced expense. In many instances, Medicaid would be underwriting the considerable expense of far more services and supports without the enormous contributions of these caregivers.
16. Promote Employment and Maintain Medicaid Buy-Option for Low-Income Worker Not Otherwise Eligible Coverage	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 in the community as an integral component of fostering improved health, wellness and independence. Being productive and working at a fair wage in a competitive employment setting not only enhances individual financial independence and self-worth, but also creates a heightened sense of well-being, community participation, socialization and confidence which can contribute to diminishing service and support needs and costs. Vocational assessments should be part of overall consumer assessments. Low income individuals ineligible for Medicaid based on their income and who do not have workplace coverage should not be dissuaded from working and should have the capacity to purchase Medicaid coverage as at present in most states. Therefore, "Medicaid buy-in" opportunities should still be made available under managed care financing and delivery plans to those who would otherwise meet the Medicaid eligibility threshold if they were not employed. Moreover, all states should be encouraged to offer Medicaid buy-in programs to promote employment opportunity. Additionally, managed care organizations serving Medicaid beneficiaries via government programs should be expected to be model employers in practicing affirmative action in the hiring of qualified workers with disabilities. Section 503 of the Rehabilitation Act requires affirmative action among federal contractors in the hiring of qualified candidates with disabilities. Contractors to Medicaid, a federal-state partnership program that provides significant services to those with disabilities, should take similar responsibility for achieving fairness in the employment of those with disabilities.