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.

Successfully Enrolling People with Disabilities in Managed Care Plans

Guiding Principles

Faced with growing caseloads, declining federal aid, and spiraling health care costs, many states are electing to enroll high-cost individuals with chronic disabilities in Medicaid managed health and long-term service plans. They are doing so in an attempt to place program expenditures on a more sustainable course while simultaneously improving the quality and accessibility of services. The National Council on Disability (NCD) recognizes that managed care techniques can create a pathway toward higher quality services and more predictable costs, but only if service delivery policies are well designed and effectively implemented, and achieve cost savings by improving health outcomes and eliminating inefficiencies, not by reducing the quality or availability of care. Designing and operating a managed care system for children and adults with chronic disabilities poses unique challenges given the highly diverse, wide ranging health and long-term support needs of the disability population. Those challenges multiply when a state attempts to create a unified system of acute health and long-term services that merges Medicare and Medicaid funding streams.

In the current state and federal policy environment where reducing public expenditures is a primary aim of public policy, there is a significant risk that vulnerable people with disabilities will be the victims of poorly conceived and executed public policies that fail to meet their needs. If such results are to be avoided, it is essential that the principles articulated below are meticulously observed in designing and carrying out managed care initiatives involving people with chronic disabilities. Done right, all stakeholders will benefit.

I. PERSONAL EXPERIENCE AND OUTCOMES

A. COMMUNITY LIVING

PRINCIPLE #1: ***The central organizing goal of system reform must be to assist individuals with disabilities to live full, healthy, participatory lives in the community.***

1331 F Street, NW ■ Suite 850 ■ Washington, DC 20004
202-272-2004 Voice ■ 202-272-2074 TTY ■ 202-272-2022 Fax ■ www.ncd.gov

For every American, sound, stable health is essential to living a rich, productive life. Individuals with chronic disabilities are among the primary victims of the nation's fragmented health care delivery system, with its lack of emphasis on health promotion, prevention, early intervention and the provision of a coordinated array of primary and specialty health services. This lack of emphasis, and the frequent denial of health maintenance services, such as, by way of example, maintenance oriented physical therapy for people with physical disabilities, or personal care supports to help independently living people to exercise or prepare healthy meals, is frequently detrimental to the long-term health and successful community living of these individuals. The resulting health decline can not only sabotage community living, employment, and participation, but can allow the development of acute or serious illness resulting in a far greater cost of the system overall.

The focus of both health care and long term supports must be to enable individuals with disabilities to live as independently as possible and to participate fully in community life, both now and throughout their lives. It is essential that enrollees in Medicaid managed care plans receive medical and non-medical supports that promote health and wellness and their capacity to reside as independently as possible in fully integrated community settings rather than in institutions and congregate care facilities.

B. PERSONAL CONTROL

PRINCIPLE #2: *Managed care systems must be designed to support and implement person-centered practices, consumer choice, and consumer-direction.*

People with disabilities must be able to control their own lives and choose services and supports consistent with their personal goals and aspirations. Service policies must be person-centered. They must honor the preferences of the person and respect each individual's right to control his or her own life by offering a flexible array of high quality, personalized services and supports from which to choose.

Person-Centered Practices. Person-centered approaches are designed to assist an individual to plan their life and supports; to increase their personal self-determination, improve their own independence, and support their social inclusion in the community. The provision of health care and long term supports and services must be designed and delivered through a person-centered lens. Health services must be carefully synchronized with long-term supports based on a common set of outcomes spelled out in each participant's person-centered plan. The plan must enable the person to exercise control over activities of daily living and health maintenance functions.

Self-Direction. A state's comprehensive managed care plan must offer enrollees with disabilities the option of overseeing their own direct services and supports and controlling their own budgets, consistent with the provisions of a person-centered plan. This option must include the exercise of control over services and supports related to critical life functions, including activities of daily living, health maintenance, community participation, and employment. In addition, individuals choosing to self-direct their services must receive the training and support needed to effectively perform required functions. In order to promote maximum independence, state officials and representatives of managed care organizations should join individuals with disabilities in advocating for amendments to overly restrictive nurse practice laws and regulations. Flexibility in these areas will provide the opportunity for creative approaches to self-directed care, which, when directed by an individual with best knowledge of his or her own needs, can greatly improve health outcomes, and will often be more cost effective over the long term.

Individual Choice. A key aim of managed care is to replace high cost services or programs with equally effective lower cost alternatives. The intimate nature of long term supports furnished to people with intensive needs requires the direct involvement of consumers in selecting the individuals to provide the services as well as the services to be delivered. Managed care benefit packages, therefore, must offer people with substantial, chronic disabilities choices among community based services, as well as the providers of such services and the locations where they are offered.

C. EMPLOYMENT

PRINCIPLE #3: ***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.***

Competitive employment at prevailing wages not only enhances an individual's sense of self-worth and economic well-being but often results in reductions – sometimes sharp reductions -- in service costs and support needs. Employees also have opportunities to build relationships that strengthen their social ties with others and enable them to become contributing, valued members of the community. One key policy aim, therefore, must be to broaden employment among people with disabilities by providing the necessary supports both in and out of the workplace and eliminating disincentives in order to enable them to enter or re-enter the work force.

D. SUPPORT FOR FAMILY CAREGIVERS

PRINCIPLE #4: ***Families should receive the assistance they need to effectively support and advocate on behalf of people with disabilities.***

Family members play critical roles in supporting and advocating on behalf of individuals with disabilities. Given government funding constraints and the growing shortage of workers available to provide direct, hands-on supports, the role of family caregivers is likely to expand in the years ahead. It is essential that family members receive the information, counseling, training and support they require to carry out their responsibilities. State policies also should permit family caregivers to be paid for providing services when such remuneration is in the best interest of the individual with disabilities, as well as providing potential cost savings to the taxpaying public, by ensuring better, more efficient care than might be available from an outside provider in that community, and so promoting the health of the individual.

II. DESIGNING AND MANAGING A MANAGED CARE SYSTEM

A. STAKEHOLDER INVOLVEMENT

Principle #5: ***States must ensure that key disability stakeholders -- including individuals with disabilities, family members, support agency representatives, and advocates -- are fully engaged in designing, implementing and monitoring the outcomes and effectiveness of Medicaid managed care services and service delivery systems.***

Active, open and continuous dialogue with all affected parties offers the best prospects for creating and maintaining a service delivery system that meets the needs of people with disabilities. All participants must be confident that the transition to a managed care system will yield better outcomes for people with disabilities. The involvement of disability stakeholders should not end with approval of a state's managed care plan. Instead, stakeholders should participate in monitoring the implementation of the plan and provide feedback on system performance and needed plan modifications on an ongoing basis.

B. CROSS-DISABILITY, LIFE-SPAN FOCUS

PRINCIPLE #6: ***The service delivery system must be capable of addressing the diverse needs of all plan enrollees on an individualized basis, including children, adolescents and adults with physical disabilities, intellectual and developmental disabilities, traumatic brain injuries, mental illnesses, substance use disorders, and other types of severe, chronic disabilities.***

The demographic and need profiles of Medicaid beneficiaries with disabilities are incredibly diverse. The types of services and supports required by an 85 year old widow with advanced Alzheimer's disease are entirely different than those needed by a teenager with significant behavioral and communication challenges caused by autism or another serious neurological disorder. Both individuals may require specialized medical services and prescription medications in combination with ongoing personal assistance. But, the composition and competencies of the team assembled to deliver those services will be radically different in the two instances, as will the types of medical, psychological, pharmacological and social interventions deemed appropriate. A key test of the potential effectiveness of a state's managed care plan, therefore, is the extent to which it includes credible strategies for serving ALL sub-populations of Medicaid beneficiaries with disabilities who are to be enrolled in the plan. One-size-fits-all approaches won't work.

C. READINESS ASSESSMENT & PHASE-IN SCHEDULE

PRINCIPLE #7: ***States should complete a readiness assessment before deciding when and how various sub-groups of people with disabilities should be enrolled in managed care plans. A state's phase-in schedule in turn should be based on the results of this assessment.***

Existing disability service systems are highly complex, with administrative structures, operational capabilities and financial arrangements varying widely from population group to population group and from state to state. Creating a unified financing and service delivery system capable of addressing the diverse health and long-term support needs of people with disabilities is an enormously complicated undertaking. Plan components must be designed and implemented with great care if disastrous consequences for the participants are to be avoided. If a state's goal is to administer Medicaid-funded health services and long-term supports under a single managed care umbrella, state officials must work with disability stakeholders, to assess existing methods of financing and delivering specialized services to covered disability sub-

populations (e.g. individuals with physical disabilities, children and adults with intellectual and developmental disabilities, persons with serious and persistent mental illnesses and substance abuse disorders, etc.). The aim of this assessment should be to pinpoint modifications in existing facilities, programs, services and administrative policies and practices that will have to occur prior to conversion to a managed care format. The results of this assessment should be used in establishing a synchronized implementation schedule. Consideration should be given to population-based or geographic-based phase-in schedules to ensure that adequate time and attention are devoted to essential implementation activities and compliance with related contractual obligations are carefully monitored by the state.

D. PROVIDER NETWORKS

PRINCIPLE #8: ***The network of providers enrolled by each managed care organization should include those who furnish health care, behavioral health and, where applicable, long term supports. The network must encompass both providers of institutional and home and community-based supports. Each network should have sufficient numbers of qualified providers in each specialty area to allow participants to choose among alternatives.***

Special attention is needed to ensure that service providers have the capacity and expertise to address the racial and ethnic diversity of the populations being served as well as cultural and linguistic barriers to access. Care also must be taken to establish and maintain adequate provider networks in rural areas of a state, afford people with disabilities a voice in the selection of network providers (possibly through advisory bodies at the state and MCO levels), and provide access to out of network services when necessary to enable enrollees to receive all needed services, including any supports or services identified as promoting community living and long-term health.

E. TRANSITIONING TO COMMUNITY-BASED SERVICES

PRINCIPLE #9: ***States planning to enroll recipients of long-term services and supports in managed care plans should be required by CMS to include providers of institutional programs as well as providers of home and community-based supports within the plan's scope of services. This requirement should be built into the "terms and conditions" governing waiver approvals.***

In recognition of the ADA requirements as interpreted by the U.S. Supreme Court in its Olmstead ruling, states should be required by CMS to detail in their

demonstration/waiver requests the steps that will be taken to effectively transition eligible individuals with disabilities from long-term care institutions to home and community-based settings.

F. COMPETENCY & EXPERTISE

PRINCIPLE #10: ***The existing reservoir of disability-specific expertise, both within and outside of state government, should be fully engaged in designing service delivery and financing strategies and in performing key roles within the restructured system.***

State Medicaid officials should draw upon the knowledge and skills of their colleagues in state behavioral health, developmental disabilities, vocational rehabilitation, education, housing, transportation, and other agencies in designing a Medicaid managed care system that builds upon decades of experience in serving various sub-populations of people with disabilities. Moreover, lead responsibility for planning and overseeing the delivery of specialized services and supports to sub-populations should be assigned to these disability-specific agencies. Another key objective of the state's managed care plan should be to expand and improve the effectiveness and efficiency of existing community disability service networks, thereby taking full advantage of the extensive knowledge and experience that exists within private community service agencies.

G. OPERATIONAL RESPONSIBILITY & OVERSIGHT

PRINCIPLE #11: ***Responsibility for day-to-day oversight of the managed care delivery system must be assigned to highly qualified state and federal governmental personnel with the decision-making authority necessary to proactively administer the plan in the public interest.***

Managed care should not be viewed as a means by which state policymakers divest themselves of their constitutional and statutory responsibilities for ensuring that recipients of publicly-funded services and supports, as well as the general taxpaying public, are effectively served. State policymakers must ensure that an adequate number of qualified state personnel are in place to monitor the system and hold managed care organizations and their sub-contractors accountable for their performance. It is vitally important that managed care contracts contain clear, unambiguous performance standards, operating guidelines, data reporting requirements, and outcomes expectations so that contractors and sub-contractors can be held to the contract specifications. Such outcomes expectations should include improvement, or at the very

least parity, in long-term health of the population served, and steady improvement in transition to community living. A state-of-the-art management information system is essential to effectively administering a managed care system (e.g., maintaining electronic records; tracking incidents; and establishing payment rates) as well as in carrying out many key state monitoring, oversight and enforcement functions.

H. CONTINUOUS INNOVATION

PRINCIPLE #12: ***The federal government and the states should actively promote innovation in long-term services and supports for people with disabilities.***

The American health care system is undergoing substantial changes as policymakers seek to ensure that all citizens gain access to affordable health care. There is no shortage of proposals to improve the quality and cost-effectiveness of services to Medicare and Medicaid beneficiaries with chronic disabilities. But, most of these proposals focus primarily on improving the organization and delivery of health care services, while giving little or no attention to gaps and discontinuities in the nation's long-term services and supports system. Building a strong, resilient community-based infrastructure to support individuals with disabilities is an essential part of creating a sustainable health care delivery system. To achieve this objective, federal and state policymakers must stimulate and nourish innovative approaches to: (a) improving access to and utilization of generic and government services; (b) forging creative public-private partnerships both within and across service delivery systems; (c) promoting better use of natural and community resources; (d) exploring opportunities to accomplish essential support functions more effectively and economically; and (e) broadening the definition of services and supports to include those services which promote, maintain, and support long-term health and healthy community living, and in so doing to create a healthier population, more economical for all.

I. MAINTENANCE OF EFFORT & REINVESTING SAVINGS

PRINCIPLE #13: ***CMS should rigorously enforce the ACA "maintenance of effort" provisions in granting health and long-term service reform waivers. The agency should require that any savings achieved through reduced reliance on high-cost institutional care, reductions in unnecessary hospital admissions and improved coordination and delivery of services be used to extend services and supports to unserved and underserved individuals with disabilities.***

Tens of thousands of individuals with disabilities across the nation lack access to the high quality health care and long-term supports they need, as evidenced by the long waiting lists for services existing in most jurisdictions across the country. It is imperative, therefore, that savings achieved through improvements in the delivery of services and supports be redirected to assisting individuals who currently are denied access to essential health care and long-term supports. In addition, health reform waiver/demonstration programs should not be used as a means to circumvent the provisions of Section 2001(b) of the ACA, which requires states to maintain Medicaid "eligibility standards, methodologies, and procedures" through 2014 for adult beneficiaries and through 2019 for childhood beneficiaries. Managed care entities must ensure that the acute and long term support needs of individuals with disabilities that were being met by the fee-for-service system continue to be met following the transition to managed care.

J. COORDINATION OF SERVICES & SUPPORTS

PRINCIPLE #14: ***Within a well-balanced service system, the delivery of primary and specialty health services must be effectively coordinated with any long-term services and supports that an individual might require.***

The most appropriate organizational arrangement for coordinating health care and long-term supports will vary according to the needs of the individual as well as the population being served. Managed care enrollees with complex chronic health conditions should be assigned a health care coordinator with specialized knowledge and experience in assisting individuals with disabilities. The designation of a health care coordinator, however, does not preclude the need for a knowledgeable individual to assist in planning and monitoring an individual's long-term, community-based services and supports. Medical oversight of the treatment process is essential when the need for ongoing social or other supports is a direct consequence of untreated or ineffectively managed chronic health conditions, as often is the case for many elderly and chronically ill individuals. By contrast, the most pressing need among the vast majority of younger individuals with physical, developmental, behavioral and sensory disabilities is for assistance in establishing and maintaining a productive, rewarding life in the community, and access to the services and supports that will enable them to stay healthy. A state's managed care plan, therefore, must include administrative, financing and service delivery arrangements which accommodate the wide ranging service and support needs of distinct segments of the disability population, including both primary and specialty health services and long-term supports. In instances where health care and long-term services and supports are separately financed and administered, written

agreements must be in place spelling out the collaborative steps each system will take to ensure that the health care and long-term services and support needs of the individual are synchronized.

III. MANAGED CARE OPERATING COMPONENTS

A. ASSISTIVE TECHNOLOGY & DURABLE MEDICAL EQUIPMENT

PRINCIPLE #15: ***Participants in managed care plans must have access to the durable medical equipment and assistive technology they need to function independently and live in the least restrictive setting.***

A state's managed care plan must afford individuals with disabilities access to the durable medical equipment and assistive technology that they require to live the most independent, inclusive, and healthy lives feasible in their community of choice. Covered services must include professional assessments of a beneficiary's need for such equipment as well as set-up, maintenance and user training.

B. QUALITY MANAGEMENT

PRINCIPLE #16: ***The state must have in place a comprehensive quality management system that not only ensures the health and safety of vulnerable beneficiaries but also measures the effectiveness of services in assisting individuals to achieve personal goals.***

A state's quality management system, at a minimum, should address:

- System Capabilities. A state's quality management system must be capable of: (a) continuously monitoring the performance of all managed care contractors and subcontractors and ensuring that prompt remedial actions are taken when deficiencies are identified; (b) reporting, tracking, investigating and analyzing incident patterns and trends in order to pinpoint and promptly remediate threats to the health and safety of managed care beneficiaries; (c) assessing the quality of services and supports provided on an individualized basis using valid and reliable clinical and quality of life measures, such as morbidity, mortality, health related incidents and deaths, reduced use of emergency care and high-cost inpatient services, quality of life, and individual and family satisfaction; and (d) preparing and issuing periodic statistical

reports on personal outcomes and system performance, analyzing trends and manage quality improvement initiatives.

- Person-Centeredness. Monitoring strategies must be developed to ensure that: (a) assessments and plans are person-centered; (b) services are delivered according to the provisions of the plan; (c) services are tailored to achieve outcomes desired by the individual, meet the individual's needs and are modified as his or her needs change; and (d) people with disabilities are free of abuse, neglect, discrimination and exploitation.

- Qualified Personnel. A state must retain a sufficient number of qualified personnel to carry out the quality monitoring and enforcement activities spelled out in its Quality management (QM) plan in an efficient and effective manner.

- Information Technology. State-of-the-art information management systems should be employed to assist state officials, managed care organizations and individual service providers in monitoring the quality of services and supports provided to managed care beneficiaries.

IV. PARTICIPANT RIGHTS

A. CIVIL RIGHTS COMPLIANCE

Principle #17: ***All health care services and supports must be furnished in ADA-compliant settings.***

Managed care enrollees with disabilities must have ready access to all services and sites where Medicaid services are provided. Such sites and services must be in full compliance with the requirements of the Americans with Disabilities Act and the Rehabilitation Act as interpreted by the U.S. Supreme Court in its Olmstead ruling, including physical, cognitive and sensory accessibility standards. In addition, all modes of public transportation used to convey beneficiaries to and from such sites must meet the ADA's transportation accessibility standards. Services must not only be accessible but must also be culturally and linguistically appropriate. Communication, family customs, preferences and relationships must be respected and factored into individual service plans.

B. CONTINUITY OF MEDICAL CARE

Principle #18: ***Enrollees should be permitted to retain existing physicians and other health practitioners who are willing to adhere to plan rules and payment schedules.***

Beneficiaries should be allowed to select a new primary care physician (PCP) at any time they are dissatisfied with their current physician, have a medical specialist serve as their PCP when circumstances warrant, and be afforded periodic opportunities to change managed care plans. Continuity of health care is important, as is the sanctity of the patient-doctor relationship. Consequently, plan participants should be afforded opportunities to retain existing health practitioners whenever possible, switch primary care physicians and health care coordinators when they are dissatisfied, and change managed care plans at periodic intervals.

C. DUE PROCESS

Principle #19: ***Enrollees with disabilities should be fully informed of their rights and obligations under the plan as well as the steps necessary to access needed services.***

States should develop and implement an aggressive education and outreach strategy to ensure that all managed care plan enrollees (and potential enrollees) have accessible information concerning the services and supports available under the plan and how they may be accessed. The state's strategy should include enlisting community-based disability organizations in developing and implementing the outreach plan. Accessible multi-media educational materials and training sessions should be geared to the various learning styles and comprehension levels of plan enrollees and such sessions should be held across the state. Managed care plan participants must receive accessible, meaningful and clear notices about programs, services and rights including enrollment rights and options, plan benefits and rules, coverage denial, appeal rights and options, and potential conflicts that may arise from relationships between providers, suppliers and others.

D. GRIEVANCES & APPEALS

Principle #20: ***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 plan should include procedures for ensuring the timely resolution of enrollee complaints and mechanisms to ensure that individuals will not be placed in jeopardy while disputes are being resolved. Appeals should comply with all existing Medicaid requirements, except in the case of plans serving dual eligibles when Medicare provisions afford stronger protections to enrollees than Medicaid rules.