CONSORTIUM FOR CITIZENS WITH DISABILITIES

PRINCIPLES AND RECOMMENDATIONS FOR TRANSITIONING PEOPLE WITH DISABILITIES INTO MEDICAID MANAGED CARE

May 11, 2012

Introduction

The undersigned members of CCD are extremely concerned about the fast pace at which many states are proceeding with mandatory Medicaid managed care models for people with disabilities. The pace is largely motivated by cost-reduction pressures, and CCD is particularly alarmed at the assumption that these populations can be exposed to *mandatory* managed care without requirements in place to protect these beneficiaries. CCD concerns focus on issues that must be addressed in order to successfully implement managed care of primary, acute, behavioral, and long term services and supports for individuals with disabilities of all ages

Managed care for people with mental and physical disabilities and chronic conditions (hereafter referred to as "people with disabilities") must be based—to the maximum extent possible—on individual choice, person-centered planning, and consumer self-direction. This is particularly important for people with disabilities who are covered by Medicaid or are dually eligible for Medicaid and Medicare (hereafter referred to as persons covered by "Medicaid"), especially when transition to managed care arrangements is mandated rather than voluntary.

This document details CCD's over-arching principles and recommendations that must be central in the development and implementation of Medicaid managed care proposals and plans that include health care and long term services and supports for people with disabilities. These subpopulations of the Medicaid program are complex, require significant services and devices, and are often among the programs' most vulnerable enrollees. Until Medicaid managed care programs are able to demonstrate their ability to effectively manage the care of people with disabilities, CCD opposes the mandatory transitioning of people with disabilities and chronic conditions into managed care.

Individuals with disabilities are a diverse population and include people with physical, sensory, intellectual, developmental, mental, or behavioral disabilities, as well as co-occurring conditions. Some individuals have lifelong disabilities that occur at birth, while others acquire their conditions through disease, chronic illness, or injury due to trauma or other accident. Individuals

with disabilities who depend solely on Medicaid and/or Medicare for health and long term services and supports tend to be among the lowest income individuals in the country and, because of their extensive and complex needs, may require a broad range of services and supports that last a lifetime.

When designed, implemented, and monitored effectively, comprehensive risk-based managed care offers opportunities for improving effective and meaningful access to and quality of care while constraining costs. However, there is limited experience and expertise to date on including persons with significant disabilities in Medicaid managed care to address their diverse health care needs and, in particular, their needs for long term services and supports. For instance, under most state Medicaid programs, traditional health care services are augmented with a wide variety of services intended to improve functional status, assist in transportation, assist in gaining the ability to live independently and work. Traditional managed care programs and plans simply lack the experience of providing services to people with disabilities with these needs under a Medicaid benefit package. As such, there has been limited development of effective quality measures specific to individuals with disabilities to ensure that these populations are being well served. For these reasons, we have strongly opposed mandatory managed care for these beneficiaries.

Endorsing Organizations

ACCSES
American Association of People with Disabilities
American Association on Health and Disability
American Academy of Physical Medicine and Rehabilitation
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Network of Community Options and Resources
American Occupational Therapy Association
American Physical Therapy Association
American Speech-Language-Hearing Association
Association for Assistive Technology Act Programs
Association of University Centers on Disabilities
Bazelon Center for Mental Health Law
Brain Injury Association of America
Corporation for Supportive Housing
Center on Disability Issues & the Health Professions
Disability Rights Education & Defense Fund
Easter Seals
Epilepsy Foundation of America
Health & Disability Advocates
Institute for Educational Leadership
Lutheran Services in America Disability Network
Mental Health America
National Alliance on Mental Illness
National Association of State Head Injury Administrators
National Council on Aging
National Council on Independent Living
National Disability Rights Network
National Down Syndrome Society
National Multiple Sclerosis Society
NISH
Paralyzed Veterans of America
The Arc of the United States
United Spinal Association

Principles and Recommendations

Establishing Protections for Individuals with Disabilities and Chronic Conditions

Principles:

Managed care must be based on individual choice, person-centered planning, and consumer self-direction, which includes personal budgeting and oversight of one's direct services and supports. These are strategies that have been piloted by the Centers for Medicare and Medicaid (CMS) in coordination with selected states for several years with very positive results. Participation by people with disabilities in Medicaid managed care should be strictly voluntary until such time that a state can demonstrate that through objective measures capacity and competence to serve the unique needs of a disability population. Once a state is able to demonstrate such capacity and competence, individuals who may be automatically enrolled into Medicaid managed care must be able to opt-out of their plan immediately if their health and functional needs are not being met. The process for choosing, developing, and holding accountable a managed care system for people with disabilities must be completely transparent and accountable to individuals with disabilities and chronic conditions.

Recommendations:

1. States must delineate their goals for transitioning people with disabilities into managed care arrangements or systems. These goals should include enabling individuals with disabilities to live full, healthy, participatory lives in the community.

2. States should establish a panel of qualified consumer advisors independent of any plan, including individuals with disability expertise, to advise the state, relevant managed care plans, providers, and consumers of their rights and obligations.

3. States must formally involve stakeholders in the development, design, implementation, monitoring, evaluation and renewal of managed care services, systems and contracts. Key stakeholders include beneficiaries, their chosen representatives, families, service providers, advocates and other impacted groups.

4. States should adopt qualitative data metrics on the managed care entity's ability to coordinate acute and post acute care, as well as the full complement of Medicaid waiver services, including home and community based services and supports. For instance, managed care plans must be able to demonstrate the ability to provide quality services and attain high consumer satisfaction levels. Managed care plans should routinely report their performance using such metrics. Failure to reach a certain quality threshold should result in meaningful enforcement action by the state to correct the problem. Results must be shared with stakeholders and the general public within reasonable time frames to

allow for outside analysis and evaluation.

5. Managed care systems must fully inform enrollees with disabilities (and their families or chosen representatives) of their rights and obligations under the plan as well as the steps necessary to access needed services. The information should be made available before enrollment deadlines. The information should be provided in multiple concise, understandable, and accessible formats (for enrollees with disabilities as well as those with limited English proficiency), and every effort should be made to avoid multiple submissions to enrollees, particularly submissions which are inconsistent and create confusion and uncertainty.

6. Grievance and appeal procedures that safeguard individual rights under the provisions of the managed care plan and all applicable federal and state statutes should be established that take into account physical, intellectual, behavioral and sensory barriers. Individuals should have access to independent entities for assistance in navigating these procedures. The procedures should authorize a state agency to make final decisions in the event the state believes the plan's refusal to provide services should be overruled.

7. States should adopt definitions of Medical Necessity that allow coverage of and promote individual services and supports designed to assist individuals with disabilities to attain or maintain sufficient levels of function that achieve individualized, person-centered goals of inclusion, participation, productivity, independence, and/or recovery. Definitions of medical necessity must be completely and publicly transparent.

Ensuring Access to Appropriate Care and Qualified Providers

Principles

States' managed care systems must be able to accommodate the wide range of service and support needs of the disparate segments of the population of people with disabilities. The provider network must have adequate numbers of experienced and qualified providers of primary and specialty health care, behavioral health care, and long term services and supports, including home and community based services, so that participants can obtain care without excessive travel or unreasonable delays in scheduling appointments. Choice of provider is a key factor in ensuring quality of care, especially for the disability population, which tends to develop close and long-lasting relations with providers who come to understand the intracacies of addressing the particular needs of people with disabilities. If health care and long term services and supports are financed and administered separately, systems must ensure coordination and continuity of care across systems.

Recommendations

1. States must perform systems preparedness assessments before deciding when and how sub-populations of people with disabilities should be enrolled in managed care. This is absolutely critical if a state intends to proceed with mandatory Medicaid managed care of people with disabilities. In conducting the assessments, the state must ensure that sufficient time and attention are devoted to ensuring adequacy of service delivery across disabilities and ages, monitoring contractual obligations, assessing quality of services, responding to feedback from participants, and ensuring participant health and safety. If and when a readiness assessment results in such assurances, states should determine whether a phase-in schedule for implementation is warranted. Even if it is determined that mandatory managed care can be implemented safely and effectively, people with disabilities must have a right to opt-out immediately if their needs are not being met under the managed care model.

2. Before implementing managed care of long term services and supports, the state must develop and have in place a comprehensive quality management system that continuously gathers, evaluates and monitors performance data of contractors and subcontractors. Independent third party consumer and family monitoring teams should be formed and utilized as part of the quality management system to perform on-going evaluations and assessments of the effectiveness of managed care in supporting beneficiaries in living full, healthy, participatory lives in their communities. Quality management data must be transparent and readily available to the public.

3. The state must provide strong administration and oversight of the managed care system, particularly when mandatory managed care is implemented. The state must employ sufficient qualified staff with experience in addressing the needs of individuals with disabilities. The state must obtain regular input from stakeholders. The state's responsibility for day-to-day oversight of the managed care delivery system must be clearly delineated in managed care contracts.

4. 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.

5. States should require managed care systems for people with disabilities to cover the full range of services and supports needed to address the diverse needs of people with disabilities on an individualized basis across the life span. The benefit package should build upon existing services and supports needed by beneficiaries to live in the community, including services for acquiring, restoring, maintaining and preventing

deterioration of function or acquisition of secondary disabilities. Information about the benefits and any limitations imposed on the benefits should be readily available to the public.

6. States must hold managed care entities accountable for continually responding to the choices of people with disabilities. States should encourage these entities to develop innovative strategies to improve the health and independent living outcomes for individuals with disabilities.

7. When a managed care entity coordinates care for individuals whose primary needs are met through long term services and supports, the managed care entity should utilize effective and well-accepted models (i.e., a home health model) that reflects appropriate weight on home and community based services and providers.

8. Enrollees should be permitted to retain their *existing* practitioners for health and long term services and supports to ensure continuity of care for at least one year, regardless of whether these practitioners participate in a managed care program. If a health practitioner is willing to adhere to the plan rules and payment schedules, an individual should be able to continue in that practitioner's care. Therefore, Medicaid managed care plans should strive to adopt into their provider networks all practitioners and suppliers who currently serve the Medicaid disability population, assuming these providers meet the provider competency and quality requirements adopted by the state.

9. Individuals with disabilities often require multiple medications and treatments to address their health conditions and need access to a robust and affordable pharmacy benefit. Medicaid managed care plans should be required to adhere to existing access protections in the Medicare Part D program.

10. Participants in managed care must have access to durable medical equipment (DME), prosthetics, orthotics, supplies and assistive devices and technologies that are needed to function as independently as possible. Access to these devices and related services must be based on diagnosis and individual need determined through qualified evaluation by appropriate professionals. Periodic assessments must be performed in order to ensure that specialized equipment facilitates maximum function and independence and does not exacerbate the participant's condition with recurrence or development of secondary disabilities.

11. Working-age enrollees must receive services and supports needed to gain and maintain employment as an integral component of improved health, wellness and independence with a preference and presumption of competitive, integrated employment. States should

continue to provide "Medicaid buy-in" opportunities to those who would otherwise meet the Medicaid eligibility threshold if they were not employed.

Ensuring Managed Care Systems do not Discriminate against People with Disabilities

Principles:

All health care services and supports provided through managed care arrangements must be accessible to people with disabilities and must be provided in the most integrated setting appropriate to the needs of the individual. States must monitor managed care plans to guard against adverse selection of beneficiaries with especially high and expensive needs.

Recommendations:

1. The state, managed care plans, and contracted providers must ensure that there is full compliance with the Americans with Disabilities Act (ADA) and Rehabilitation Act non-discrimination provisions and the requirements for physical and programmatic access. This includes accessible health care facilities, diagnostic and therapeutic equipment, and all health care settings considered public accommodations. All facets of a state's managed care program must also comply with the US Supreme Court's Olmstead decision, which upheld the ADA's integration mandate.

2. Families should receive the assistance they need to effectively support and advocate on behalf of people with disabilities. If appropriate for the individual, state policies should permit payment to family members and informal caregivers for providing services and supports.

3. States planning to enroll recipients of long term services and supports in managed care plans must include all resources and services related to institutional as well as home and community-based programs within the plan's scope of services. In order to increase positive outcomes for beneficiaries and maximize cost-savings, institutional services and the resources associated with them must not be "carved out" of managed care plans.

4. States must use savings realized through system improvements such as care coordination and reduced use of institutional care to address the needs of those individuals waiting to receive services and to expand coverage of benefits under the category of long term services and supports. Reinvestment strategies should reflect stakeholder input and be publicly articulated in the managed care application and the contract with the state. Any Medicaid savings must be reinvested for the covered population and may not be used to address other state budgetary shortfalls or other acute care needs.

5. Capitation rates must be based on the total expenditures for the covered population over a multi-year period. Rates must incorporate techniques such as risk corridors, risk adjustment, and stop-loss insurance to ensure that there are no disincentives for enrolling beneficiaries with high needs. In addition, a strong opt-out provision must be available to any person with a disability under Medicaid managed care, particularly when enrolled through a mandatory process.

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