



July 6, 2012

The Honorable Kathleen Sebelius  
Secretary  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Hubert H. Humphrey Building  
Washington, DC 20201

**RE: Transitioning People with Intellectual and Developmental Disabilities into Mandatory Medicaid Managed Care**

Dear Secretary Sebelius:

ACCSSES is concerned about the fast pace at which some states are proceeding with mandatory Medicaid managed care for people with intellectual and developmental disabilities (I/DD). These individuals often depend solely on Medicaid for the long term services and supports they need to remain healthy, functional, and independent. Because of their extensive and complex needs, these individuals may require a broad range of services and supports throughout their lifetime.

ACCSSES members are service providers devoted to serving individuals with I/DD. Our members have developed significant and important expertise in this service delivery sector. The pace at which States are embracing mandatory Medicaid managed care for people with I/DD—a population that has largely been carved out of managed care efforts in the past—is largely motivated by current budgetary pressures. We understand these pressures and appreciate the opportunity to work collaboratively with states and CMS to design and implement effective reforms. However, in states that have implemented managed care for people with I/DD, the outcomes are mixed, at best.

Some states have experienced extremely poor outcomes for people with I/DD in Medicaid managed care. For example:

- Wisconsin's program for people with I/DD is struggling in some parts of the state because capitation rates for its managed care organizations (MCOs) are set based on correlations between claims data and an assessment that does not capture all of the needs of people with I/DD, not on the actual costs of providing services. This has resulted in several rounds of rate cuts and unnecessary relocations of individuals with I/DD from stable homes and community-based programs to unfamiliar environments with caregivers that lack historical knowledge on their needs. In fact, Wisconsin often excludes service providers who have extensive knowledge of and experience with the needs and desires of the people they serve from its care management teams, which are responsible for creating

person-centered plans.

- Because Kansas was implementing managed care for this population on a very fast track, advocates objected until the Kansas legislature delayed by one year the inclusion of I/DD services into the mandatory Medicaid managed care model. In fact, when the state requested proposals from managed care organizations, Blue Cross Blue Shield decided not to bid the I/DD population because they did not have sufficient experience in providing services to people with I/DD. In explaining their decision, Blue Cross wrote to the Kansas Medicaid office, “It would require us to dramatically change our business model to serve new populations in different settings in less than a year. We decided we could not responsibly commit to so great a change at this time.”

However, some states’ experience with Medicaid managed care for the I/DD population has shown that when well designed, Medicaid managed care can be an effective and efficient method of providing services to the I/DD population. Michigan, for instance, has carved out the I/DD population from its traditional Medicaid managed care program and applied a more targeted approach. This has worked successfully for over ten years. The success of Michigan’s program is largely attributed to the utilization of an existing public, non-profit and county-based system very familiar with the I/DD population and services, rather than a private managed care company focused on primarily acute health care services.

As a national organization of providers dedicated to providing high quality services to people with disabilities, ACCSES must insist that states modify plans to transition people with I/DD into mandatory Medicaid managed care to include essential consumer protections for this high-risk and unique population. To be successful, this process must involve LTSS provider specialists in the ongoing development, implementation and evaluation of these protections. ACCSES believes that mandatory Medicaid managed care should not be considered the only solution to addressing rising health care costs and improving service delivery; these goals can be accomplished through a number of delivery models and changes to the healthcare system.

Attached below are ACCSES’s proposed protections for people with I/DD in mandatory Medicaid managed care, and we welcome any questions you might have regarding this document. We would also appreciate the opportunity to meet with you this summer to discuss our recommendations for consumer protections, and to explore other delivery reforms that could achieve the goal of improving care and decreasing costs for individuals with I/DD. We will be in touch with your office to arrange such a meeting.

Thank you for your consideration of our views. Please do not hesitate to contact Theresa Morgan, ACCSES Legislative Director, with any questions at [Theresa.Morgan@ppsv.com](mailto:Theresa.Morgan@ppsv.com) or (202) 466-6550.

Sincerely,



Terry R. Farmer  
CEO, ACCSES

CC:

Marilyn Tavenner, Acting Administrator, Centers for Medicare and Medicaid Services  
Sherry Glied, Assistant Secretary for Planning and Evaluation  
Kathy Greenlee, Administrator, Administration for Community Living  
Sharon Lewis, Commissioner, Administration on Intellectual and Developmental Disabilities  
Peter Kemper, Deputy Assistant Secretary, Office of Disability, Aging and Long-Term Care Policy  
Cindy Mann, Deputy Administrator and Director, Center for Medicaid and CHIP Services  
Henry Claypool, Principal Deputy Administrator, Administration for Community Living  
Jamie Kendall, Deputy Commissioner, Administration on Intellectual and Developmental Disabilities  
Melanie Bella, Director, Federal Coordinated Health Care Office  
Richard Gilfillan, Director, Center for Medicare and Medicaid Innovation  
Kirsten Beronio, Director, Division of Behavioral Health and Intellectual Disabilities Policy  
Barbara Edwards, Director, Disabled & Elderly Health Programs  
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Mike Hall, Director, Division of Integrated Health Systems  
Nancy Klimon, Deputy Director, Division of Integrated Health Systems

## PROTECTIONS FOR BENEFICIARIES WITH DISABILITIES IN MEDICAID MANAGED CARE

1. State and Federal Oversight: The state must provide strong administration and oversight of the managed care system, particularly when mandatory managed care is implemented. Prior to approving plans for mandatory Medicaid Managed Care, a state should create an oversight body to regularly monitor, assess and recommend changes to Medicaid Managed Plans for people with I/DD. This body should have representatives of the state, consumer advocates for people with disabilities, providers and specialists familiar with the range of services provided to people with disabilities, as well as representatives of non-profit association insurance plans. The federal government also has a major responsibility approve state plan amendments that seek to implement mandatory managed care for the I/DD population *only* when the U.S. Department of Health and Human Services is convinced that people with I/DD will be adequately protected and will receive services in the appropriate amount, duration, and scope.
2. Assessment of Capacity to Serve the I/DD Population: States must perform systems preparedness assessments, or “readiness reviews” before deciding when people with I/DD should be enrolled in mandatory managed care. States should require MCOs to work with an accreditation body to assess the plans for their ability to serve this population, such as reviewing the expertise of the MCO staff to ensure understanding of the basis for intellectual and developmental disabilities services. Additionally, each plan should be required to demonstrate that it has under contract a sufficient network of providers, suppliers, and a wide range of community-based nonprofit service organizations with experience serving the relevant consumer population that is capable of providing all Medicaid benefits that the State is considering placing under Medicaid mandatory managed care. For people with I/DD, there should be a special emphasis on demonstrating capacity for those Medicaid waiver services that extend beyond the traditional acute care medical services that health plans have provided in the past, including, where appropriate:
  - a. Home and community based services and supports
  - b. Personal care and attendant services
  - c. Rehabilitation and habilitation services and devices
  - d. Mobility equipment and related services
  - e. Adult day services
  - f. Pre-vocational services
  - g. Transportation related to the provision of covered services
  - h. Home modifications for accessible and safe living
  - i. Respite care services
3. Performance Measurement: The state oversight body’s initial and ongoing assessment of whether managed care plans are adequately meeting the needs of individuals with I/DD requires the development of systems measures to assess the readiness and performance of MCOs and provide for the public reporting of this data on an ongoing basis. States should

use appropriate assessment tools, such as the [Supports Intensity Scale](#) (SIS), for determining resource allocation and planning for individuals with I/DD. The assessment tool selected by the state should be a valid measure of the supports needed for successful community living, instead of placing the focus on deficits in functioning or on problem identification. It should empower the individual to become more engaged and identify areas in which natural or generic supports may be provided.

The systems measures that are developed should gauge consumer satisfaction and program performance. The systems measures used by the state should include determinations for *at least* the following capabilities of the managed care plans and its provider network:

- a. To provide timely acute and preventative care, if the plan includes those services, as well as the traditional home and community-based waiver services to people with disabilities;
  - b. To provide coordinated quality care to at-risk and vulnerable populations;
  - c. To maximize service provision in the home and community-based setting with an emphasis on independent living;
  - d. To meet the functional needs of people with disabilities, as well as the medical needs if acute services are included in the plan;
  - e. To accommodate the unique needs of people with I/DD on Medicaid;
  - f. To achieve acceptable levels of consumer and family satisfaction with the services, as measured every 6 months with consumer-friendly tools like [uSPEQ](#); and
  - g. To examine person-centered plans on a regular basis to determine if the needs, preferences, and choices of people with I/DD are being met.
4. Person-Centered Plan: An updated written, person-centered plan that includes necessary non-medical services should be required before the individual joins or rejoins a Medicaid managed care plan. Each managed care plan must be able to demonstrate a person-centered planning process in which the support needs of each beneficiary are fully considered. States must evaluate the adequacy of the planning process used by the MCOs to meet these specialized needs and the quality of the person-centered plan to meet needs, preferences, and choices.
  5. Stakeholder Engagement: CMS should require States to formally engage key stakeholders (service providers, beneficiaries, their chosen representatives, families, advocates and other impacted groups) in the development, design, implementation, monitoring, evaluation and renewal of managed care services, systems and contracts.

States should involve stakeholders through regular stakeholder meetings that take place at least twice a year and should use their findings to impact and update the managed care services in order to ensure the program meets the needs of people with disabilities. States should be required to report how they address and respond to stakeholder concerns.

6. Managed Care Plan Compliance: The state agencies should closely monitor and assess plan compliance. Public reporting of data related to transition and implementation of managed care should be displayed on accessible websites (and available in accessible formats upon request) in order to ensure transparency and accountability. The health departments should also be required to provide annual public reporting to legislatures, consumer protection and advocacy organizations, and the community at large with respect to its monitoring and enforcement efforts. Finally, these agencies should have explicit enforcement authority to:
  - a. suspend enrollment of additional people with disabilities at any time with cause;
  - b. compel managed care plans to take specific steps to meet the needs of people with I/DD;
  - c. suspend state contracts with managed care plans until remedial actions are taken to address deficiencies;
  - d. permanently suspend managed care plans' involvement with mandatory Medicaid managed care of people with I/DD; and,
  - e. create an adequate backup plan for continuity of care in the event an MCO fails or is suspended.
7. Risk Sharing, Reinsurance, and Fiscal Solvency: CMS should require states to develop adequate risk-sharing and reinsurance policies to support plans and managed care programs that cover individuals with I/DD. The risk-sharing and reinsurance policies will help to maintain financial solvency of the MCOs and ensure people with I/DD are not unjustly cut from these plans if coverage for high-cost individuals (outliers) is provided within the plan, instead of as an exception to it. It will also ensure that if required services are provided that exceed the MCO's capitation revenue that MCOs will not underfund these services to make up for the revenue shortfall. States should be required to share in the risk and provide contributions to the reinsurance policies.
8. Transparent Rate Setting Process: CMS should require states to provide a mechanism for oversight of changes to the capitation levels and reimbursement rates for services provided to people with I/DD. The process should be transparent, and plans should look to actual cost data from providers as the basis for the determination of "actuarial soundness." Since changes to the capitation levels and reimbursement rates may signal fiscal problems, CMS should evaluate all plans closely with reimbursement changes to the MCOs and/or their provider networks for the determination of actuarial soundness and financial viability.
9. Maintaining Beneficiary-Provider Relationships: 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. States should require plans to work with community-based nonprofit consumer and provider organizations with expertise and experience in assisting people with I/DD, such as aging and disability resource centers, independent living centers, and community rehabilitation programs.

10. Public Accountability: Managed care plans that serve the Medicaid disability population, as well as the dual eligible population in the coming years, should be required to be and remain publicly accountable.
11. Use of Proven Models: 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.
12. Development of Best Practices: In order to learn about how managed care delivery systems affect people with disabilities, CMS should conduct a longitudinal study to determine the best practices for managed care for people with I/DD. Through these studies, CMS may be able to create a separate best practices model to service this population. Over time, through stakeholder engagement and continual quality measurements, CMS can develop a managed care model or other service models that can best serve people with I/DD. Other service delivery systems for this population should be compared to managed care, including standard fee reimbursement systems, self-determination, accountable care organizations and others that may arise as alternatives to managed care to see which has the greatest utility in meeting the unique needs of this population.