

National Council on Disability

**Medicaid Managed Care  
Community Forums: Final Report**

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## Acronyms Glossary

ACA	Patient Protection and Affordable Care Act
ADA	The Americans with Disabilities Act
CBO	Community-Based Organization
CFC	Community First Choice
CMS	Centers for Medicare and Medicaid Services
FFS	Fee-for-service
GAO	General Accounting Office
HCBS	Home- and community-based services
HHS	U.S. Department of Health and Human Services
I/DD	Intellectual and developmental disabilities
MCO	Managed care organization
MLR	Medical loss ratio
MLTSS	Managed long-term services and supports
MMC	Medicaid managed care
P&A	Protection and Advocacy nonprofit groups advancing legal rights of people with disabilities
SHIP	State Health Insurance Program
UI	Urban Institute

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## Executive Summary

“People with disabilities are particularly sensitive to small changes in access to health care; [some] have needs that differ substantially from the needs of other Medicaid beneficiaries.”<sup>1</sup> Could this population—people with disabilities—be the canaries in the health care system’s coal mine? Data is sparse on the fallout and perspectives of disability stakeholders when new policies, procedures, and practices are thrust upon vulnerable people. As states face budget constraints, Medicaid managed care programs for seniors and people with disabilities have gained increasing attention across the country.

In studying the emerging Medicaid issues, the National Council on Disability (NCD) has focused its attention on how changes and proposed changes in delivery systems from planning through implementation are affecting people with disabilities. NCD began articulating its earliest findings and recommendations in 2012 with publication of *Analysis and Recommendations for the Implementation of Managed Care in Medicaid and Medicare Programs for People with Disabilities and Guiding Principles: Successfully Enrolling People with Disabilities in Managed Care*,<sup>2</sup> followed in 2013 by its report, *Medicaid Managed Care for People with Disabilities: Policy and Implementation Considerations for State and Federal Policymakers*.<sup>3</sup>

As a direct follow-up to NCD’s 2012 and 2013 Medicaid managed care publications, in fiscal years 2014 and 2015, NCD hosted a series of stakeholder forums to promote greater dialogue and contact between key CMS regional office staff and the disability community regarding managed care waiver applications and dual eligible demonstration proposals. This work was achieved through 10 community forums in which state Medicaid authorities, the U.S. Department of Health and Human Services (HHS) Centers for Medicare and Medicaid Services (CMS), and over 650 people participated. There were seven stakeholder groups comprising consumers/self-advocates, families, other advocates, providers, informal family caregivers, state government agency workers, managed care organizations (MCO), researchers, and various professionals in academia.

NCD conducted the Medicaid managed care forums in 10 states (KS, FL, IL, CA, NY, GA, LA, PA, TX, and WI) with the following goals:

1. Facilitate input on experiences, preferences, and desired outcomes for Medicaid managed care among disability leadership, federal and state agency representatives, health plans, providers, and consumers;
2. Educate the public by promoting Medicaid managed care principles outlined in the NCD 2013 report;
3. Assess consumer satisfaction and perspectives on what seems to be working;
4. Identify early challenges and gaps in care occurring under new delivery systems;
5. Summarize and disseminate the forum proceedings and stakeholder input;
6. Highlight NCD's Medicaid managed care recommendations to states, CMS, and Congress; and
7. Build upon federal agency partnerships around changes that need to be made in federal legislation and/or rule governing Medicaid managed care.

This report reflects the perspectives of what disability stakeholders, self-advocates, parents, providers, and state Medicaid staff are experiencing at the state and community levels. The experiences of Medicaid beneficiaries provide important additional data points to available information already documented in the academic and policy literature.<sup>4</sup> Across states implementing Medicaid programs along with managed long-term services and supports (MLTSS) in which NCD held forums, disability-related concerns consistently emerged as unmet needs. To fully serve people with disabilities in the future, managed care decision makers and providers must address these issues.

Effective solutions to concerns identified will require collaborative actions by local people, state governments, CMS, and NCD's Medicaid managed care (MMC) forum findings and recommendations generally involve, but are not limited to: (1) the protection of people with disabilities from adverse unintended consequences of MMC programs and processes; (2) improvements applicable to the general design and implementation of the program at the state level and across all populations who utilize MLTSS; and (3) revisiting federal legislation and rules to provide clarity and consistency, supporting federal Medicaid managed care policy directives to the states.

# Introduction

In 2014, U.S. federal and state governments spent more than \$475 billion on services for Medicaid recipients.<sup>5</sup> The magnitude of the Medicaid programs that serve many of the most vulnerable individuals demands accountability, and many states, feeling the pressure to control costs, are implementing or planning to implement forms of managed care for their Medicaid programs. States enroll seniors, people with disabilities, and children with specialized physical health care needs in programs that offer dental care, behavioral health care, transportation, and pharmacy services under Medicaid managed care.

State-by-state, the transition to an MMC system is a challenge because of a change from how stakeholders have worked together in the fee-for-service (FFS) system to how they will need to collaborate differently in the future. The inclusion of long-term services and supports in the MMC system is particularly challenging because of the inexperience of states across the country in implementing an “all-in” system. Therein, states such as Illinois decide to set up long-term services and supports for eligible seniors and people with disabilities (both institutional and home- and community-based care) in combined managed care models.<sup>6</sup> Best practices, standardization, and demonstrated outcomes of these MLTSS models are beginning to emerge.

Where MLTSS programs exist, the arrangements are diverse throughout the country. The designs include several sub-population groups, a variety of contractors, and degrees of integration across services. The variations include programs with capitated payments for limited Medicaid benefits, comprehensive Medicaid benefits, and comprehensive Medicaid and Medicare benefits.

Historically, managed care arrangements have excluded people with disabilities who use long-term services and supports because of their complex needs. Now, however, some states are also moving this population to managed care. Most states have incorporated long-term services and supports-specific measures into their quality management programs. However, the lack of a nationally endorsed set of measures has resulted in an array of approaches from state to state.<sup>7</sup>

Little is known or written about the experiences of people with disabilities during and after this transition, making this NCD information-gathering project extremely important because it documents experiences of Medicaid enrollees with disabilities who use long-term services and supports during transition to Medicaid managed care.

Different entities have conducted studies in recent years, exploring the use of managed care for Medicaid long-term services and supports. Most studies base findings on policy reviews and interviews with providers, advocates speaking *for* beneficiaries, legislators, and Medicaid agency staff. Only NCD's studies, however, report data gathered directly from the Medicaid beneficiaries, including people with disabilities themselves.

NCD's stakeholder forums one through five, held between December 2013 and June 2014, were located in Topeka, KS; Tallahassee, FL; Chicago, IL; Sacramento, CA; and New York, NY. NCD conducted five more forums in Atlanta, GA; Baton Rouge, LA; Philadelphia, PA; Austin, TX; and Madison, WI, which concluded in August 2015.

Through the MMC forums, NCD heard about best practices as well as challenges/gaps in care for Medicaid managed care and long-term services and supports beneficiaries. To serve people better in the future, the U.S. Department of Health and Human Services (HHS) Centers for Medicare and Medicaid Services (CMS), the states, or the MCOs must address the issues with input from other stakeholders. During forum presentations, however, CMS representatives maintained that a state has the primary responsibility for administering and monitoring the Medicaid managed care program<sup>8</sup> and that CMS works to preserve a state's flexibility in implementing Medicaid managed care.

Ensuring that effective Medicaid managed care plans are developed and implemented with consideration of the needs of people with disabilities will require changes in policy and operations, plus strong stakeholder partnerships. Forum participants made it clear that CMS must continue to put a strong focus on bringing the culture and essential elements of community-based long-term supports into managed care, emphasizing person-directed access to health care, independent housing, employment (supported and competitive), and other inclusive community living options for all Americans.

As states move to expand Medicaid managed care to include more people with disabilities, it will be essential that the new delivery systems are structured to preserve the principles of home- and community-based services (HCBS). HCBS systems must emphasize choice and consumer-driven care and services, demonstrate real progress in developing community-based infrastructure, and actively promote community-based options.

Specifically, the NCD forums sought to answer the following questions:

1. What are the experiences with managed care of Medicaid beneficiaries with disabilities?
2. How can Medicaid managed care be designed to advance health care and community-based supports for people with disabilities?
3. What are concerns of disability stakeholders about the potential pitfalls of Medicaid managed care?
4. What are the essential principles and precepts that disability stakeholders want to see in the Medicaid managed care system serving people with disabilities?
5. What criteria should federal officials use in regulating state managed care plans and reviewing and approving related waiver requests?
6. How can disability advocates play constructive, influential roles in shaping the contours of state managed care initiatives affecting people with disabilities at the state Medicaid authority level and with the CMS?

The report is divided into three chapters and a conclusion. Chapter 1 provides NCD's recommendations for the states, CMS, and Congress to improve services, ensuring that people with disabilities in Medicaid managed care have access to health care and long-term supports. Chapter 2 summarizes the findings from NCD's 10 Medicaid care forums conducted between December 2013 and August 2015. Chapter 3 provides NCD's recommendations for consideration by disability advocates. Available data and findings from the forum panels and open discussions support NCD's position that now is the critical time to examine the approaches to providing Medicaid managed care.

# **Chapter 1. Recommendations for U.S. Department of Health and Human Services Centers for Medicare and Medicaid Services, Congress, and States**

The primary sources for NCD's recommendations are stakeholder input, available research, and existing Senate Committee recommendations that NCD also supports. In this chapter, NCD presents recommendations for actions regarding: (1) protection of people with disabilities from adverse unintended consequences of Medicaid managed care programs and processes; and (2) application to the general design and implementation of the programs at the state level across all populations who utilize MLTSS. This chapter also incorporates some best practice considerations that may benefit federal Medicaid managed care policy directives to the states. NCD proposes that federal and state policymakers initiate the recommendations that follow to ensure that people with disabilities gain access to the full array of health and long-term services and supports they need while enrolled in Medicaid managed care programs.

## **Recommendations to HHS/CMS**

1. CMS should direct states to financially support stakeholder engagement and assistance in the construction and development of Medicaid managed care plans at the initial inception and support ongoing consumer engagement and feedback.
2. Within existing funds and allocation of Medicaid appropriations, CMS should establish a sufficiently funded program within the federally mandated Protection and Advocacy (P&A) agencies to ensure Medicaid managed care programs at the state level are protecting the rights of consumers.
3. CMS should mandate that states adequately fund an independent ombudsman's office.
4. CMS must require states to clearly indicate a mechanism for monitoring MCO compliance with the state contract and in compliance with federal law.

5. To facilitate greater state and health plan compliance with the Americans with Disability Act (ADA), CMS should convene a workgroup of the disability community to write a model ADA compliance plan that provides guidance to MCOs.
6. CMS should require a medical loss ratio; MCOs must spend at least 85 percent of premiums on medical claims and quality improvements.
7. CMS should prohibit states from carving out any public or private institutions from the managed care framework and should increase the incentives for community-based care.
8. CMS should enforce the “maintenance of effort” requirement in the Patient Protection and Affordable Care Act (ACA), which requires states to reinvest savings achieved by lowering institutional admissions and returning residents to the community in expanding access to, and the quality of, home- and community-based supports.
9. CMS should require states to ensure that MCOs maintain a maximum ratio of care coordinators to beneficiaries, as well as address other network adequacy issues.

## **Recommendations to Congress**

1. Congress should authorize CMS to direct states to financially support stakeholder engagement and assistance in the construction and development of Medicaid managed care plans at the initial inception and support ongoing consumer engagement and feedback. Congress should address funding needs for implementation and direct CMS to require that states provide CMS with a state plan for engaging stakeholders from a broad spectrum of identified categories, including people with disabilities.
2. Congress should increase appropriations to the federally mandated P&A agencies in each state by an additional \$5 million to hire health advocates to increase monitoring and advocacy.

3. CMS should be allotted the personnel required to review, approve, and oversee implementation of state managed care waiver/demonstration programs and carry out its other related statutory responsibilities.
4. Congress should restructure Medicaid laws governing long-term services and supports to eliminate the bias toward institutional services and should instead emphasize person-centered community supports designed to promote the inclusion of beneficiaries with disabilities in the mainstream of American society.
5. Congress should amend the Medicaid statute to require every state that participates in the program to pay for HCBS for those who are eligible, just as every state is required to pay for nursing homes.
6. Congress should require clear and uniform annual reporting of the number of individuals served in the community and in institutions, together with the number of individuals transitioned and the type of HCBS living situations into which they are transitioned.
7. Congress should require incremental state spending goals for national Medicaid long-term services and supports for 2016, 2020, and 2025 to ensure that the proportion of spending on HCBS continues to increase. Congress should increase the federal share of Medicaid expenditures for states that achieve these benchmarks and reduce the federal share for states that do not.<sup>9</sup>
8. Congress should amend ADA provisions to clarify and strengthen the law's integration mandate in a manner that accelerates *Olmstead v. L.C.* implementation and clarifies that every individual who is eligible for long-term services and supports under Medicaid has a federally protected right to a real choice in how they receive services and supports.
9. Congress should direct CMS to develop ways to share models of state level engagement that show evidence of working for the benefit of the people who are receiving Medicaid managed care services.
10. Congress should take action that supports CMS action directing states to provide adequate funding of an independent ombudsman's office to include funds for complaint and grievance resolutions.

## Recommendations to the States

1. States should financially support stakeholder engagement and assistance in the construction and development of Medicaid managed care plans at the initial inception and support ongoing consumer engagement and feedback.
2. States should adequately fund an independent ombudsman's office.
3. States should clearly indicate a mechanism for monitoring MCOs.
4. States should organize technical assistance to the MCOs on culturally competent care policies in Medicaid consistent with The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (The National CLAS Standards).<sup>10</sup>
5. States should rely upon disability policy experts in the design and implementation of Medicaid managed care plans involving beneficiaries with disabilities.
6. State legislatures should appropriate enough funding to the state Medicaid authority so that they have the resources to hire the necessary qualified personnel to design, implement, and monitor managed care contracts.
7. Payment to the MCOs should be adequate to support the goals of MLTSS programs, including the essential elements established in this document, such as the delivery of high-quality services in home- and community-based settings, and support the goal of community integration, as well as MMC contracts that provide performance-based incentives tied to outcome measures and penalties for poor performance or noncompliance.

## Chapter 2. Summary of NCD Findings from the Ten Medicaid Managed Care Forums

NCD's overall objectives for the forums focused on obtaining stakeholder perspectives. In preparation for each venue, NCD council members, federal agency partners from CMS, and regional and state presenters combined efforts for meaningful stakeholder dialogue. Across the locations, stakeholders expressed appreciation for explanations of NCD's *Guiding Principles* publication.<sup>11</sup> Each forum's agenda featured panel presenters and facilitated discussions among disability leadership, self-advocates' family members, federal and state agency representatives, health plans, and providers. Overall, participants described experiences, preferences, and desired outcomes for improving Medicaid managed care. Appendix A provides highlights from the agendas for each location and identifies the participants who served as presenters on relevant topics.

In addition, NCD uncovered a number of universal themes across the 10 states. Forum participants reported issues on Medicaid managed care systems covering access to health care and long-term services and supports; stakeholder engagement; grievance and appeals processes; network adequacy; ADA compliance by MCO programs and providers; and a general lack of MCO understanding of the complex individual needs of people in the long-term services and supports system. These recurring themes in every forum demonstrate that states and CMS need to closely monitor the MLTSS system. Stakeholders also told NCD that they need to see CMS place greater emphasis on ensuring that: (1) people are getting adequate minimal care, such as needed medical supplies and personal care hours; and (2) the goal of HCBS is advanced through MLTSS to enable individuals to remain in their homes, improve their quality of life, and avoid excessive hospitalization or placement in nursing homes or treatment facilities.

Advocates at NCD's 10 MMC forums expressed concern that lack of access to long-term services and supports leads, not just to difficulties for the individuals, but often to greater costs for families and the state when hospitalizations increase. Forum participants indicated that the MLTSS system needs a lot of attention and monitoring by federal and state officials. Those policymakers have assumed that people are

continuing to receive their necessary services during the transition to MMC systems, but disability stakeholders warn that this has not universally been the case. Stakeholders also stated that among their MLTSS needs are technical assistance with model contracts, readiness reviews, and quality measures.

Along with the universal themes are descriptions of 18 other topical areas mentioned by forum participants. The topics include Protection and Advocacy Needs; Stakeholder Engagement; Independent Ombudsman; Constitutional Due Process; ADA Compliance Plan Guidance; Culturally Appropriate Access to Care; Transparency and Accountability; Home- and Community-Based Care; Rebalancing Expenditures Between Institutions and Community-Based Services; MCO Care Coordinators; Network Adequacy; Supported Employment; Increased Bureaucratic Procedures Under MLTSS; MLTSS Inclusion of Community-Based Providers; MCO Competencies; Readiness Reviews; Quality Measures; and Model State Medicaid Managed Care Contracts. Summaries of the information shared by stakeholders regarding these 18 topics are included in the paragraphs below.

**1. Protection and Advocacy Needs:** NCD heard calls from forum participants for better access to specialized health advocates, given the complex nature of Medicaid managed care. Health advocates would serve as “boots on the ground” to ensure that managed care systems comply with federal law and work with the states’ Medical Care Advisory Committees to obtain and publicize information about managed care to beneficiaries.

**2. Stakeholder Engagement:** A technical assistance document by CMS states that “continuous engagement of stakeholders is critical to success. This includes stakeholders external to state government, such as beneficiaries who use LTSS, advocates, long-term services and supports providers, and those internal to state government, including aging and disability agencies, the insurance oversight agency, the Governor’s Office and the Legislature.”<sup>12</sup> Similarly, the advisory councils (at the state or managed care planning levels) must include such stakeholders. Across the NCD forums, stakeholders—especially people with disabilities and advocacy organizations familiar with disability needs and issues—repeatedly told NCD about their

lack of opportunities for such involvement. People with disabilities shared with NCD their desires and need to be included during discussion and planning of managed care, rather than being subjected to programs and processes that did not have their input.

Participants confirmed that many traditional MCOs lack experience with the Medicaid population, which includes people with disabilities who also may have low incomes and complex health and social needs. This makes direct involvement of people with disabilities and other advocates critical. Funding must be made available to meaningfully involve consumers, family members, and their advocates in concrete planning, evaluation, and governance activities at local and state levels. Consumers and their advocates bring grounded knowledge about needs and the effective solutions to address these needs, including what is culturally, linguistically, and disability sensitive.

State plans should provide staff support and stipends for time and transportation to help consumers and advocates participate. Federal regulations require Medicaid programs to provide Medicaid Medical Care Advisory Committees with “staff assistance from the agency and independent technical assistance . . . [and] financial arrangements, if necessary, to make possible the participation of recipient members.”<sup>13</sup> This requirement for support goes beyond federal requirements for public hearings and comment periods on federal waivers and demonstration projects.

Several states are already using best practice consumer engagement strategies.<sup>14</sup>

- Wisconsin requires one-quarter of each MCO board in its Family Care program to be Medicaid beneficiaries or their advocates.
- Massachusetts requires at least one consumer on the board of each MCO in its Senior Care Options program. It also requires each MCO to have a consumer advisory committee to help guide its new duals demonstration for people with disabilities; the state has also proposed an implementation council with at least 51 percent consumer representation.

- In Arizona, New Mexico, New York, and Tennessee, regulations or contracts require MCOs to establish member councils or to include consumers on advisory committees in their long-term services and supports plans.
- North Carolina requires its nonprofit management agencies to provide support to a Consumer and Family Advisory Committee.

**3. Independent Ombudsman:** As of 2015, the establishment of an ombudsman for Medicaid managed care was not a condition of receiving waiver approval from CMS. The programs are state-initiated, and therefore there is no uniformity among the states in how the ombudsman functions and under what authority it operates. There is considerable diversity in state systems for receiving complaints from Medicaid managed care enrollees. In accordance with established best practices, the state ombudsman programs overseeing the Medicaid managed care program should be located outside of any agency that administers or manages Medicaid services. Advocates expressed to NCD strong preferences and needs for an independent ombudsman office, which they perceive as having a greater degree of autonomy than currently exhibited. However, this autonomy cannot be equated with less authority to resolve problems. The independent ombudsman must have the authority to take action to resolve issues. Forum attendees stated that information gathered through the ombudsman program must be fed directly into the state's Medicaid office's contract management and oversight departments. This information would be in addition to the information that is obtained by monitoring the formal hearings or the MCO complaint process. In this function, the ombudsman program not only assists beneficiaries to resolve their issues but supports state monitoring of the MCOs. Grievances and complaints, whether lodged formally or informally, can serve as an early warning system and can highlight flaws in the design of the overall system. Several state practices reveal how ombudsman programs should operate, as referenced in these examples from the Community Catalyst article:<sup>15</sup>

- Wisconsin consumer advocates pressed for an ombudsman when their state proposed to expand managed long-term services and supports in 2006. The state enhanced the role of its federally required institutional long-term-care ombudsman to include complaints from people 60 and older receiving community

based services. In addition, the state contracted with Disability Rights Wisconsin to operate an ombudsman program for people 18 to 59 getting Medicaid [long-term services and supports]. Disability ombudsmen across the state handle individual cases while a program manager identifies systemic problems in Medicaid [long-term services and supports].

- Hawaii contracts with a nonprofit advocacy organization to serve as ombudsman for its managed care programs.
- New York is proposing an ombudsman program modeled on the Wisconsin program to serve its managed long-term services and supports and duals demonstration programs.<sup>16</sup>

**4. Constitutional Due Process:** Problems arise when Medicaid-covered services are subject to prior authorization, and an increasing number of people with disabilities and chronic conditions are having their services subjected to prior authorization. All Medicaid beneficiaries, including those enrolled in managed care plans, are entitled to written notice and an opportunity for a hearing before an adverse action is taken against them.

Forum participants reported that frequently services are being terminated during the authorization period (usually 60 to 90 days), while the individual's appeal is pending, and due process protections are not being considered under Medicaid managed care. Letters to state Medicaid directors, webinars, on-site training, and audits are all needed to remind MCOs of the requirements of the Constitutional Due Process mandates, and CMS must clearly emphasize to states the expectation that authorized long-term services and supports services continue pending appeal. In no state was this more apparent than in Kansas. Stakeholders reported repeated denials or delay of vital services. (See Appendix C for a summary of the public hearing NCD held on the Medicaid managed care plan in Kansas.) NCD heard that the Kansas system is less efficient and more bureaucratic than before. It used to take less than a week to get someone crisis services; now it takes 21 days just to get an approval. Approvals for all services now take two to three times longer than before.

**5. ADA Compliance Plan Guidance:** People with disabilities cannot derive a full and equal benefit from publicly funded health insurance unless health plans comply with laws protecting their civil rights. An analysis completed by the Center for Independence of the Disabled New York found that MCOs were out of compliance with ADA requirements.<sup>17</sup> NCD heard similar complaints during the Medicaid managed care forums in Illinois, Kansas, California, and New York. In other states, forum participants reported that accommodations have not been made by the MCOs for the Deaf and Hard of Hearing or the blind. Sign interpreters, Communication Access Realtime Translation services, and accessible publications are rarely made available.

CMS has the responsibility to provide the states guidance on ADA compliance to ensure that Medicaid health plans identify barriers to care and provide reasonable accommodations and full programmatic accessibility. CMS should develop, along with people with disabilities, a model ADA compliance manual. The guidance must include what managed care plans are already required to do, such as:

- Identify enrollees with disabilities in order to provide reasonable accommodations that are necessary to avoid discrimination.
- Give notice of how disability is defined with examples of disabilities that include functional limitations (e.g., trouble standing, ongoing sadness, difficulty with reading).
- Describe what kinds of accommodations are available (providing examples that are nonexclusive).
- Ensure that personnel are trained to provide accommodations.
- Include a network of providers with accessible practices.

CMS must direct states to:

- Assign responsibility for compliance activities within their Medicaid agencies, including regularly updating ADA compliance guidelines that contain clear and detailed guidance on baselines for compliance; a model compliance plan; and member handbook language.

- Provide or require plans to obtain training for grievance and appeal personnel, member services personnel, case managers, and other relevant personnel to receive training on disability literacy, ADA, and compliance plan requirements.
- Have adequate personnel to review ADA compliance plans, issue statements of deficiency, and review and approve plans of correction with clear timelines for compliance, provide or arrange for technical assistance, and test compliance with ADA compliance plan provisions.
- Report to CMS and the public on progress toward ADA compliance in the managed long-term care program.
- Require MCOs to develop a brochure for enrollees regarding ADA rights in managed care that is distributed upon enrollment.

**6. Culturally Appropriate Access to Care:** At the forums in Florida, California, and Texas, NCD heard that those states are leading the way in ensuring that MCOs and providers value the diversity of their states and expect their MCOs to support people from diverse backgrounds, cultures, and a variety of disabilities. Providers are expected to comply with the laws concerning discrimination on the basis of race, color, national origin, or sex, limited education, low literacy skills, limited proficiency in English, culture-specific values regarding the authority of the physician, and poor assertiveness skills. These dimensions require attention in Medicaid managed care settings.

Florida, California, and Texas have implemented strategies to require managed care plans to provide appropriate services to their highly diverse Medicaid populations. For example, rather than relying upon the traditional tool of regulation, California decided to create detailed health plan contract requirements to ensure culturally appropriate care. The state also hoped to stimulate competition among commercial managed care plans by including ratings of plans' culturally competent service requirements in the competitive bidding process. Among the California contract provisions required by the state are:

- 24-hour access to interpreter services;
- translation of all written materials distributed to non-English-speaking members;

- defined threshold criteria for non–English-speaking populations requiring additional linguistic services;
- assessment of the linguistic capability of plan employees and interpreters;
- member needs assessments;
- development of cultural and linguistic services plans; and
- establishment of community advisory committees to assist in developing and monitoring culturally competent services.

**7. Transparency and Accountability:** For large employer plans, the requirement that health insurers spend at least 85 percent of premiums on medical claims or quality improvements was thought by some stakeholders to be added to ACA. However, ACA did not require a medical loss ratio (MLR) standard for Medicaid plans. On the other hand, some ACA supporters favor providing consumers with nearly \$2 billion in rebates from health insurers who did not meet the spending ratio. The supporters also point to lower premiums as insurers cut administrative costs to meet spending requirements.

In 2011, CMS required an 85 percent MLR as a condition of Florida’s waiver extension agreement, which was the first time the Federal Government has made MLR a requirement for waiver approval. The MCOs operating in Florida must provide documentation to the state and CMS to show ongoing compliance with 85 percent MLR. This action by CMS suggests that an MLR standard in Medicaid could emerge as a federal requirement as states seek to move more and more Medicaid beneficiaries into managed care on a mandatory basis. At the Florida forum, advocates expressed their support for the MLR requirement but stated that continued monitoring would be necessary to determine what is included by the MCO in clinical services as opposed to administration and profit.

Related to the issue of MLR is the move toward more financial accountability and transparency regarding the Medicaid dollars that MCOs are paid. Congress is currently considering legislation to require annual audits of these programs. CMS does not require states to audit managed care payments.

The General Accounting Office (GAO) in a recent report expressed its concern regarding this issue. “GAO recommends that CMS increase its oversight of program integrity efforts by requiring states to audit payments to and by MCOs; updating its guidance on Medicaid managed care program integrity; and providing states additional support for managed care oversight, such as audit assistance from existing contractors.”<sup>18</sup>

Some states, such as Georgia and Texas, have already established comprehensive monitoring programs, and others require audits conducted by independent auditors.<sup>19</sup>

**8. Home- and Community-Based Care:** NCD’s 2012 Medicaid managed care guiding principles document suggests: “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.”<sup>20</sup>

Participants in the forums shared perspectives on the “carve-out” for institutional settings for people with intellectual and development disabilities (I/DD), which was allowed by CMS in the Kansas waiver. Accordingly, NCD heard that such action creates harmful incentives for MCOs and diminishes the ability of the managed care framework to enhance quality and control costs. There is no programmatic rationale for the exclusion of the lowest-quality, highest-cost service from the managed care framework. The concern is that carve-outs may create perverse incentives for MCOs to shift people into institutional settings rather than keep or transition people into other home and/or community options. A Senate Health, Education, Labor, and Pensions Committee report shows that from 2000 to 2007, nursing home use increased among adults age 31 to 65 in 48 states, that nationwide the proportion of nursing home residents younger than 65 increased from 12.9 percent in 2005 to 14.2 percent in 2009, and finally that current data shows that there are still more than 200,000 individuals younger than 65 in nursing homes—almost 16 percent of the total nursing home population.<sup>21</sup>

The same committee reports failure of states to carry out several aspects of community living during the 14 years since the *Olmstead* decision<sup>22</sup> and made these recommendations involving Congress, CMS, and people with disabilities:

- Congress should amend ADA provisions to clarify and strengthen the law's integration mandate in a manner that accelerates *Olmstead* implementation and clarifies that every individual who is eligible for long-term services and supports under Medicaid has a federally protected right to a real choice in how they receive services and supports.
- Congress should amend the Medicaid statute to end the institutional bias in the Medicaid program by requiring every state that participates in the program to pay for HCBS, just as every state is required to pay for nursing homes, for those who are eligible.
- Congress should require clear and uniform annual reporting of the number of individuals served in the community and in institutions, together with the number of individuals transitioned and the type of HCBS living situations into which they are transitioned.
- Congress should require incremental state spending goals for national Medicaid long-term services and supports for 2015, 2020, and 2025 to ensure that the proportion of spending on HCBS continues to increase. Congress should increase the federal share of Medicaid expenditures for states that achieve these benchmarks and reduce the federal share for states that do not.<sup>23</sup>

Under ACA, states have new options to provide community-based services to people living in the community with chronic or disabling conditions. The first new opportunity (effective since 2011)<sup>24</sup> is the Community First Choice (CFC) 1915 (k), a new benefit under the state plan that supports community attendant care for people who have an institutional level of care with an enhanced federal matching rate of six percent.<sup>25</sup>

Available data as of January 2016 indicates that five states have received CMS approval to offer the CFC option in their Medicaid plans: California, Montana, Oregon, Texas, and Maryland;<sup>26</sup> and at least two additional states have applied for approval: Minnesota<sup>27</sup> and New York.<sup>28</sup>

## **9. Rebalancing Expenditures Between Institutions and Community-Based**

**Services:** Nationally, Medicaid spends more on institutional care than on home- and community-based care for beneficiaries with long-term services and supports needs. Rebalancing refers to the effort to achieve a more equitable balance between the proportion of total Medicaid long-term support expenditures used for institutional services and those used for community-based supports.

Advocates across the country at the 10 forums stated that they are concerned that a number of companies vying for state contracts have little or no experience dealing with people who need long-term care. They also fear that plans might try to restrict access in order to save money because many new members will require expensive services.

In May 2013, CMS issued guidance to the states on 10 elements CMS considers when evaluating state proposals to establish an MLTSS program.<sup>29</sup> The guidance requires states establishing managed care systems to support rebalancing and to develop quality measures focused on outcomes. NCD has learned from the information gathered at the forums that there is no consistency across states, and no state has implemented the comprehensive set of measures needed to capture the impact managed care is having on rebalancing.

The elements that CMS believes must be in place to support rebalancing are:

- Adequate planning and transition strategies;
- Stakeholder engagement;
- Enhanced provision of HCBS to include effective options for community and workforce participation<sup>30</sup> (adding to what is already covered/required under the ADA and the *Olmstead* decision of the U.S. Supreme Court: Medicaid beneficiaries are entitled to receive services in the most integrated setting<sup>31</sup>);
- Payment to managed care plans supporting MLTSS program goals;
- Person-centered processes;
- A comprehensive and integrated service package;
- Qualified providers; and

- Quality factors (a comprehensive quality strategy and oversight structure that takes into consideration the acute and primary care, behavioral health, as well as long-term services and supports needs of beneficiaries, and can provide a framework for states to incorporate more meaningful goals into the program that focus on quality of care and quality of life for beneficiaries).<sup>32</sup>

**10. MCO Care Coordinators:** More intensive case management may be required for specific populations, and states should be required to indicate how the current networks will be supported to assure such targeted case management services would be provided in those instances if states include people with intellectual disabilities under Medicaid managed care, and for other disability groups.

Some forum participants said that states should be required to indicate in their waivers the protections that are put in place to ensure that people with disabilities will be able to retain access to their existing targeted case managers after the transition to managed care. Ratios for care coordination for the MCOs should be established. CMS should carefully evaluate coordination for people with various types of disabilities and consider appropriate maximum ratios.

**11. Network Adequacy:** Although there are no uniform quantitative standards among states,<sup>33</sup> most have some regulatory requirements on network adequacy for health plans in part of the private market. During the NCD forums, participants shared that Medicaid beneficiaries often struggle to locate providers who are actually accepting new Medicaid patients and are forced out of (inadequate) networks to confusing out-of-network services. Participants also shared that provider directories often list providers that are not actually taking new Medicaid patients, which results in a difficult and frustrating “hunt” on the consumer’s part. Another very common issue is that state enforcement of network adequacy is passive and relies mostly on health plan self-reports and member complaints. Relying on self-reported MCO information and complaints is an inadequate approach to ensuring network adequacy.

To resolve various network adequacy issues, Texas advocates sought passage of network adequacy legislation. Senate Bill 760 passed the Texas Legislature in the 2015 Legislature.<sup>34</sup> The bill requires the following:

- Public reports that provide details about health plan networks, including provider-to-member ratios (e.g., cardiologists/1,000 members);
- State-implemented, substantial financial sanctions for health plans that fail to comply with provider access standards;
- New standards that will make provider directories more accurate and provide more assistance to members who need help locating providers; and
- Improvements to provider credentialing processes that should help more providers join health plans more easily.<sup>35</sup>

**12. Supported Employment:** In 2013, CMS issued an information bulletin on employment and employment-related services for Medicaid beneficiaries with disabilities.<sup>36</sup> The information bulletin stresses the importance of employment in the lives of people with disabilities.

Repeatedly, NCD heard from forum participants that competitive employment is very important to them. Work is a fundamental part of life for adults with and without disabilities. Work is an essential path to economic self-sufficiency and financial stability. According to multiple research studies,<sup>37</sup> work has been associated with building self-esteem and positive physical and mental health. Many people with disabilities require support to gain and maintain integrated employment.

Forum participants stressed that employment supports should be a mandatory service provided under managed care plans. The Medicaid managed care plan in Kansas, KanCare, provides incentives to MCOs who can demonstrate increased competitive employment. Wisconsin expanded access to supported employment by covering it through the Medicaid State Plan HCBS option.

**13. Increased Bureaucratic Procedures Under MLTSS:** Forum participants reported that MCOs frequently deny long-term care services and supports that were previously provided by the Medicaid FFS system. The impression is that some MCOs are very strategic in their denials and that other plans might just be careless, but the way it plays out for people in MLTSS plans is the same—services are cut substantially without notice and explanation. Some individuals who spoke at the forums were caregivers or

self-advocates who, despite requiring 24-hour care, saw their personal care hours reduced or their care discontinued altogether. They reported that when they do receive a notice of reduction of services, they are informed that the amount/level of personal care services requested is not medically necessary. MCOs may impose more stringent prior authorization on services than those imposed by the state in the FFS system. For example, MCOs may ask providers to submit more detailed justification for providing services that exceed the cost of a previously established care plan.

P&A staffs are overwhelmed by requests from beneficiaries seeking legal assistance. One P&A director referred to MLTSS in his state as death by 1,000 bureaucratic cuts.

For community-based providers of long-term services and supports, the managed care system is also difficult. For example, providers revealed that the process of negotiating contractual agreements with managed care entities is more formal and complex than the process by which long-term services and supports providers become qualified to participate in state Medicaid programs and negotiate payment rates. Managed care contracts can be lengthy and legalistic, prepared by legal and contract departments of large national corporations. On the other side of the table, the legal and contracting expertise available to small long-term services and supports providers is often quite limited.

Providers of long-term services and supports talked about new and more stringent billing practices as a particular challenge in the shift to MLTSS. Managed care entities generally use standardized claim forms for provider billing, while many states use home-grown, nonstandard claim forms for long-term services and supports. Thus, long-term services and supports providers often need training on the proper completion and submission of new claim forms in order to be paid for their services. Additionally, in contrast to preexisting FFS systems, providers may have contracts with multiple MCOs for their clientele, requiring them to become proficient at more than one billing system.

**14. MLTSS Inclusion of Community-Based Providers:** States vary in the level of preparedness by which long-term services and supports providers shift their business practices from FFS to managed care, dependent upon numerous factors. Among the

factors that contributed to the variation in preparedness were: (1) the length of time of the MLTSS implementation process; (2) the extent to which states had included requirements in their contracts with managed care entities to protect the existing long-term services and supports network; (3) the scale of the MLTSS program; and (4) the amount of technical assistance provided by states during MLTSS implementation.

While states recognize the need to support their long-term services and supports providers in the transition from FFS to MLTSS, tight implementation schedules and lack of resources can preclude states from offering much assistance to providers during the transition process. In states where there is no organized technical assistance activity, many long-term services and supports providers can be left to “fend for themselves” during the MLTSS transition process. In addition to state technical assistance efforts, however, state provider associations are also actively helping their long-term services and supports members maneuver the MLTSS transition process as smoothly as possible.

Disability stakeholders stated that they wanted Medicaid managed services and supports built around and linked to existing community-based disability structures, such as independent living centers, recovery learning communities, and community-based developmental disabilities and mental health agencies.

**15. MCO Competencies:** According to the forum participants, many managed care companies expanding into the MLTSS market have a limited understanding of long-term services and supports, and of the long-term services and supports provider community. Most managed care companies are used to contracting for acute health care services that are highly regulated and licensed. They are not used to contracting for long-term services and support services that are more socially oriented, less defined, and more tailored to the individualized needs of the long-term services and supports recipient. Further, some of the new delivery models that have been developed in long-term services and supports, such as participant-directed services, are unfamiliar to managed care entities, and do not fit into their usual contracting processes. However, the supply of managed care entities with MLTSS experience is growing.

NCD heard that MCOs have a general lack of understanding of the long-term services and supports market and the long-term services and supports provider community. Most managed care entities that are expanding into MLTSS come from a traditional health care model. Moreover, MCOs may have the misconception that managing long-term services and supports populations and long-term services and supports services is somehow “easy” relative to the management of traditional acute care services. In the world of Medicaid, they also may have the mistaken belief that most users of long-term services and supports services are frail seniors in need of nursing home or skilled home care. Many MCOs are not well-prepared to deal with the challenges of managing long-term services and supports services for younger people with disabilities, and particularly people with severe disabilities.

MCOs often lack experience in payment methods for long-term services and supports services, since the MCOs are used to paying claims for episodic acute care services, such as births, hospitalizations, specialty visits, and so forth. They are not as accustomed to paying for services that are used daily—and in some cases continuously—by long-term services and supports recipients. MCOs also may not have experience in financing 24-hour residential services for people with disabilities, including people with intellectual disabilities. Finally, states may place expectations on MCOs to develop new service models for long-term services and supports populations, particularly service models that are more cost-effective, and more person-centered than the models that have traditionally been used in the FFS system. The development of new types of service delivery models for long-term services and supports populations requires a higher level of creativity and innovation than many MCOs are used to. However, it is clear that many states are turning to MLTSS models with the hope that private sector organizations can be more innovative and creative in meeting the needs of long-term services and supports populations than is feasible within the constraints of the public sector.

**16. Readiness Reviews:** Participants in states that had a methodical and gradual rollout of their Medicaid managed care plans for long-term services and supports reported fewer disruptions in service and less confusion about the conversion of existing

disability services and supports to a managed care framework. Because disability service systems are highly complex and include supports services and not just medical services, creating a service delivery system capable of addressing the diverse health and long-term support needs of people with disabilities is consequently an enormously complicated undertaking. Managed care plan components, therefore, must be designed and implemented with great care if consequences are to be avoided. For this reason, it is important that state officials work closely with disability stakeholders to assess existing methods of financing and delivering specialized services to subpopulations of people with disabilities encompassed by the plan (e.g., people with physical disabilities; children and adults with intellectual and developmental disabilities; people with serious mental illnesses and substance-use disorders). An in-depth readiness assessment is especially important if a state's ultimate goal is to administer Medicare- and Medicaid-funded health services and long-term supports under a single managed care umbrella.

The aim of the assessment should be to pinpoint modifications in existing administrative policies and practices that will have to occur prior to (and during) conversion to a managed care format. The results of the assessment should be used in establishing a synchronized implementation schedule such as those used, for example, in Florida, New Jersey, and California. 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 and state regulations. The purpose of a readiness assessment is to ensure that all of the essential pieces are in place before the transition to managed health services and/or long-term supports occurs.

CMS and states work collaboratively to develop state-specific readiness review tools, and in theory this readiness review is supposed to be based on stakeholder feedback that states and CMS received through letters and public meetings, the content of the memorandum of understanding between CMS and the state, and state-specific procurement documents.

Forum participants reported limited participation in readiness reviews and a general lack of understanding about what should be included in readiness reviews as well. Across all

the states, participants felt that they needed technical assistance from CMS to educate them so that they could actively participate in the planning, design, and implementation of Medicaid managed care for long-term services and supports.

**17. Quality Measures:** NCD heard from disability stakeholders at the forums that the state MLTSS programs do include quality measures that are specific to long-term services and supports, but the lack of a national set of long-term services and supports measures has resulted in highly unique approaches across the states and little comparability across programs. These varied approaches without clear guidance from CMS makes it difficult for advocates at the state level to effectively advocate for best practices, such as: (1) timeliness of initiating community-based long-term services and supports; (2) timeliness of completing level-of-care assessments; (3) nursing facility or other institutional admissions; (4) maintenance of community transition; (5) receipt of services authorized in the care plan; (6) person-centeredness of care plan; (7) number of home health visits; (8) notification of appeal rights upon reduction or denial of service; (9) participation in volunteer or paid work; (10) member satisfaction; and (11) member personal experiences.

**18. Model State Medicaid Managed Care Contracts:** Participants in several states not only expressed a need for a model readiness assessment but also model contracts. NCD brought to several of the forums experts with a library of managed long-term services and contract provisions from about a dozen states.<sup>38</sup>

National experts from the National Health Law Center highlighted best practice contract provisions but cautioned forum participants that the contracts are only as good as the monitoring and oversight provided by the state. An example of this is in Florida, where, drawing on experiences from a decade of experimentation, the new Medicaid managed care plan incorporates vital consumer protections, some unique to Florida. However, these protections establish the need for ongoing oversight and public input, creating opportunities for stakeholder monitoring and comment. Participants in Florida raised the following questions to CMS: *What happens if the state does not adequately provide oversight and monitoring? What actions will be taken by CMS?* CMS continued to maintain throughout their public comments at the forums that the state has the primary

role in monitoring and oversight and that essential flexibility is given to the states in how they implement Medicaid managed care.

CMS indicates that they provide extensive individualized technical assistance for the states through state Medicaid agencies in developing, enhancing, implementing, and evaluating managed care programs.<sup>39</sup> CMS also provides a list of topics on which states may request technical assistance: developing standards and measuring provider network adequacy; quality measurement; monitoring and enforcing MCO compliance with contract provisions; MLTSS; beneficiary education/information; managing grievances and appeals; analyzing data for performance measurement; and developing or implementing information technology and systems.<sup>40</sup>

## Chapter 3. Recommendations for Advocates at the State Level: Advocacy Considerations

Since the CMS-proposed rule still leaves a lot of discretion to the states and MCOs and many areas are left undefined, there is still a lot of work that advocates will have to do at the state level once the rule is codified. Based on the information gathered at the forums held in the 10 states, NCD makes the following recommendations to advocates at the state level. Advocates should consider the potential benefit of more detailed requirements in MMC contracts, state statutes, state regulations, policies, and procedures.

### Defining MLTSS

MLTSS refers to the delivery of long-term services and supports through capitated Medicaid managed care programs.<sup>41</sup>

In several aspects of MLTSS, the proposed rule leaves a considerable amount of discretion to the states and to MCOs.

- *Specifying Services and Supports:* Advocates should seek more detail about what services and supports should be included in MLTSS, as long as the listing clearly establishes a floor rather than a ceiling.
- *Service Plans:* Notably, the proposed rule does not require a service plan for a person needing long-term services and supports. Instead, the proposed rule sets standards for planning if the state requires service plans for such beneficiaries.
- *Conflict of Interest in Service Planning:* More detail is needed on how to limit conflicts of interest in the service planning process, given the various financial interests of MCOs and providers.

### Enrollment and Disenrollment

CMS explicitly recognizes that beneficiaries are best served when they make an active enrollment decision. To this end, CMS in the proposed rule proposes consistent standards for enrollment into plans. Stakeholders should consider whether these

standards are adequate to ensure that beneficiaries can exercise informed choice and may want more specifics in the state Medicaid managed care contract.

- *14-Day Enrollment Period:* In light of the needs of the population served by Medicaid, including the level of health literacy, language proficiency, reliance on family members for assistance, and other factors, stakeholders should consider whether a 14-day enrollment period is sufficient or whether a longer amount of time is needed when making an enrollment decision.
- *Informational Notices:* The proposed rule does not address the adequacy of the informational notices that must be sent to beneficiaries regarding enrollment. Stakeholders should consider whether the informational notices should also include requirements for beneficiary testing, plain language standards, and requirements for alternative formats and translation of notices for populations with limited English proficiency.

## **Grievances and Appeals**

In the proposed rule, CMS strives to reduce the confusion experienced by beneficiaries who transition among different insurance coverage types. While advocates share this goal, alignment should not come at the expense of robust consumer protections. Stakeholders should consider whether the proposed solutions for alignment afford beneficiaries adequate protections through the appeal process.

- *Right to a State Fair Hearing:* Many states currently allow beneficiaries access to a state fair hearing upon an initial adverse benefit decision. This protection affords beneficiaries with immediate independent review of an adverse decision. Denying immediate access to this route of appeal—by requiring an internal plan appeal first—could negatively impact beneficiaries.

## **Beneficiary Support System**

While CMS is proposing a new regulatory section for the beneficiary support system, the agency notes that it does not expect states to develop an entirely new consumer network. CMS anticipates states will draw upon and expend existing resources to

develop the support system. A key question is how the existing network of consumer assistance services will be incorporated into the beneficiary support system, and whether the process will appropriately meet consumer's needs for support.

- *Choice Counseling:* States have flexibility to determine the entity that will provide choice counseling. This entity is considered an enrollment broker and must be independent of the MCO. Advocates should weigh in at the state level on the relationship between the existing State Health Insurance Programs (SHIPs) and private Medicaid enrollment contractors, and how each might function under the beneficiary support system's choice counseling provision.
- *County MCOs:* In states where a county operates a managed care plan, the conflict of interest standards prohibit the county from serving as a choice counselor. Advocates should consider how this prohibition could impact existing SHIP programs or other counseling services administered by Area Agencies on Aging or Councils on Government.
- *Training on community services:* The proposed rule requires training MCOs on community-based organizations (CBOs) the beneficiary support system, but does not detail the training's purpose. There is value to improved coordination between the MCO and CBOs. Advocates should consider how this training could improve coordination and what should be the training requirements.

## **Network Adequacy**

The factors specified by CMS in the proposed rule are relevant. The concern is whether the proposed regulations are specific enough to ensure network adequacy and practical enough to be effective.

- *Specific Standards:* Advocates should consider whether the regulations should establish any standards or guidelines for particular time and distance standards.
- *Monitoring:* Another consideration is how usable these network adequacy standards are in real life, for state agencies, MCOs, and consumers. Consider the accessibility of the relevant information and the ease (or difficulty) of making

the required determinations. A recent report by the HHS Office of Inspector General (cited by CMS in the proposed regulations) found that most states did not find *any* violation of access standards over a five-year period, and most findings of violations were based on a state’s direct testing of MCO compliance.<sup>42</sup>

- *Exceptions Process:* The exceptions process should likely be tightened or limited. It would be too easy for a contract to exempt a particular MCO based on the proposed regulations’ current language.

## **Service Authorization and Care Continuity**

CMS proposes important consumer protections that could increase access and availability of long-term services and supports services. However, the rule language is vague, raising concerns as to whether states and MCOs will interpret the proposal in a consumer-centric way. Advocates should consider the following:

- *Authority to Set Service Definitions:* CMS leaves responsibility to the state and MCOs to define and specify the amount, duration, and scope of the MCO services in the state–MCO contract. The state and MCO also have the authority to set the definition for medically necessary service in the contract.
- *HCBS Medically Necessary Service:* The contract only has to explain the MCO’s responsibility to cover services that address the “opportunity” to have access to the benefits of community living. Advocates should consider whether addressing the opportunity for community living is a sufficiently clear directive to authorize home- and community-based services as a medically necessary service and what other formulations might be more effective.
- *Utilization Management:* The proposed rule requires that utilization management “reflect” the beneficiary’s long-term services and supports needs. Advocates should consider how their state would interpret the utilization management authority and share examples of past state practice. Consider other formulations that may include assisting with meeting the need, documenting the need, or providing services to meet the need.

- *Service Authorization Consistent with Person-Centered Plan:* Similar to the above question, the requirement that MCOs authorize a service “consistent” with the person-centered service plan creates questions. “Consistent” with the plan could mean authorizing the services requested in the person-centered plan, or it could mean authorizing services that are similar to the general goals of the person-centered plan. Advocates should consider how their state may interpret this directive.
- *Care Continuity:* The care continuity requirement is unquestionably vague. Advocates in MLTSS and dual eligible states should share examples of their state’s existing care continuity requirements and discuss how the requirement could be improved.

## **Quality Measurement and Improvement**

With special regard to the public’s access to information, the proposed regulations are a substantial improvement over the current system. One concern is making sure that all the data will be meaningful for consumers in real-life situations.

- *Specificity:* Advocates will have to work at the state level to provide more specificity on recommended performance measures.
- *Private Accreditation:* One potential issue is the state’s ability to rely on private accreditation. This arguably reduces state accountability. On the other hand, reliance on private accreditation is increasingly common.
- *Quality of Life Measures:* CMS did not articulate in the rule how quality of life should be measured; consumers and consumer organizations should be sure to weigh in on this question at their state level.

## **Medical Loss Ratio and Rebalancing Between Institutions and Community-Based Care**

States and CMS have indicated that one goal of shifting to a managed care delivery model is to rebalance public spending in long-term services and supports by increasing access to HCBS services. At a high level, the rule incorporates important rebalancing

components. However, the rule does not do enough to motivate states and plans to rebalance spending toward community services, the stated goal of MLTSS. Advocates may want to consider:

- *Lack of Rate-Setting Detail:* Although the rate-setting preamble in the proposed rule includes a recommendation for sufficient rates to support rebalancing, the rule language merely states that rates must be “appropriate for the populations to be covered and the services to be furnished under the contract.”
- *Silence on Rebalancing Incentive Payments:* Beyond payment for services, there is no requirement that states use the rates to incentivize plans to promote HCBS. Further, there is no requirement that the rates be sufficient to assist individuals transitioning out of institutional settings and into the community. Advocates should reflect on their current rate-setting models and discuss their ability to pay for community transitions with state policymakers.
- *Numerator Activities:* Advocates should provide details on the kinds of activities that should be included as a community integration activity for purposes of the MLR numerator. The proposed rule does not detail the types of activities that fall under MLR.
- *Need for Rebalancing Measures:* CMS’s overall proposal for quality assessment improvement gives considerable deference to states. While the rule includes three long-term services and supports-specific quality areas, it does not recommend any long-term services and supports-specific quality measures. A joint advocate memo to CMS regarding specific rebalancing measures addresses this need.<sup>43</sup>
- *No Regulation on Olmstead:* The preamble includes a discussion that all programs be implemented consistent with ADA requirements and *Olmstead*; however, the actual regulation is silent on integrating and implementing *Olmstead* into managed care contracts and state–federal agreements.

## Conclusion

Access to appropriate health care, plus supplementary services and supports remain increasingly important to people with disabilities as Medicaid managed care expands nationwide. NCD's MMC forum participants emphasized the need for strong federal support and clear guidance. Progress in carrying out recommendations from this report will require joint stakeholder help to ensure that current and future Medicaid managed care enrollees with disabilities have the services and supports they need.

NCD recognizes that managed care can create a pathway to high-quality services and more predictable costs. A caveat is ensuring that service delivery policies and implementation are well designed with opportunity for user input.

High-quality MMC and/or MLTSS access is essential to effective health care services and long-term care services and supports. Absent adequate access enrollees will not receive the health care and support services necessary to achieve positive health outcomes and improved quality of life. NCD's MMC forum participants identified examples of specific challenges and gaps in long-term services and supports consumers. To make services fully accessible and beneficial for people in the future, an increase in coordinated efforts will be paramount to people enrolled in MMC programs. Lessons learned across the forums offer valuable insights for effective public policy and full inclusion of people with disabilities across the United States.

# Appendix A. Medicaid Managed Care Summary Agendas

Topeka, KS—Thursday, December 5, 2013

LOCATION: Kansas State House, the Old Supreme Court Chambers

**Call to Order and Welcome:** Jeff Rosen, NCD Chair  
Clyde Terry, Member, National Council on Disability

**NCD Medicaid Managed Care Principles**  
Ari Ne'eman, Member, National Council on Disability

## **Panels with Question and Answer Sessions**

### **Panel 1: Medicaid Managed Care Federal and State Agency Updates**

**Moderator** Ari Ne'eman, Council Member, National Council on Disability  
Barbara Edwards, Director, Disabled & Elderly Health Programs Group, Centers for Medicare and Medicaid Services  
James Scott, Associate Administrator for Medicaid and Children's Health Operations, Region VII, Centers for Medicare and Medicaid Services  
Steven Mitchell, Acting Manager, Office of Civil Rights, Region VII  
Laura Howard, Regional Director, Substance Abuse and Mental Services Administration, Region VII  
Shawn Sullivan, Secretary, Kansas Department for Aging and Disability Services

### **Panel 2: Disability Leadership Stakeholders**

Craig Knutson, Kansas Self-Advocate Coalition  
Hal Shultz, Kansas Self-Advocate Coalition  
Ian Kuenzi, Sunflower State Health Plan  
Finn Bullers, KanCare consumer and writer, United Spinal Association  
Eric Harkness, NAMI Board member and Disability Rights Center, Kansas board member

### **Panel 3: National Experts in Medicaid Managed Care**

Scott C. Brunner, Senior Analyst and Strategy Team Leader, Kansas Health Institute  
Merrill Friedman, Vice President, Advocacy, WellPoint  
Nancy Thaler, Executive Director, National Association of State Directors of Developmental Disability Services

## **Facilitated Discussion with Forum Invitees**

Nancy Thaler, Facilitator

Ellen Piekalkiewicz, Forum Coordinator, National Council on Disability

Call host: Kamilah Martin-Proctor, Member, National Council on Disability

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## **Building Community Systems of Care Tallahassee, FL—Friday, February 21, 2014**

LOCATION: Florida A&M University

### **Call to Order, Welcome and Introductions**

Dr. Danette Saylor, Director, Center for Disability Access and Resources, Florida A&M University

Kamilah Martin-Proctor, Co-Vice-Chair, National Council on Disability

### **NCD Medicaid Managed Care Principles**

Ari Ne'eman, Council Member, National Council on Disability

### **Panels with Question and Answer Sessions**

#### **Panel 1: Medicaid Managed Care Federal Agency Updates**

Barbara Edwards (*invited*), Director, Disabled & Elderly Health Programs Group, Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services

Stephanie McCladdie, Regional Administrator, Region IV, Substance Abuse and Mental Health Services Administration

Timothy Noonan, Regional Director, Region 7, Department of Health and Human Services Office of Civil Rights

#### **Panel 2: Medicaid Managed Care State Agency Updates**

Justin Senior, Agency for Healthcare Administration

Melanie Brown-Woofter, Agency for Healthcare Administration

Charles T. Corley, Secretary, Department of Elder Affairs

Leigh Davis, State Ombudsman, Florida Long-Term Care Ombudsman Program

#### **Panel 3: Disability Leadership Stakeholders—Policy Panel and Discussion**

**Moderator** Clyde Terry, National Council on Disability

Laura Cantwell, Associate State Director, Florida AARP

Amanda Heystek, Attorney, Disability Rights Florida

Clint Rayner, Mental Health Self Advocate

Jesse Fry, Chair, Florida HIV/AIDS Advocacy Network

**Question and Answer—Kamilah Martin-Proctor, Member, National Council on Disability**

## **Policy Panel and Discussion**

**Moderator** Ari Ne’eman, National Council on Disability

### **Panel 4: National Experts in Medicaid Managed Care**

Sarah Somers, Managing Attorney, National Health Law Program

Manuel Arisso, Chief Executive Officer, Magellan Complete Care

Merrill Friedman, Vice President of Advocacy, WellPoint

**Policy Panel and Discussion, Gary Blumenthal, NCD**

### **Panel 5: Effective and Efficient Use of State and Federal Funds to Enhance Community-Based Services and Build Community Support Systems**

Ellen Piekalkiewicz, NCD Forum Facilitator, Capital Health Strategies

Tom Rankin, Deputy Director of Operations, Agency for Persons with Disabilities

Eric Jacobsen, Executive Director, Georgia Developmental Disability Council

Paul Annino, Florida State University School of Law, Public Interest Law Clinic

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**Chicago, IL—March 24, 2014**

**LOCATION:** Access Living—115 W Chicago Avenue

### **Call to Order, Welcome and Introductions**

Amber Smock, Director of Advocacy, Access Living

Kamilah Martin-Proctor, Co-Vice-Chair, National Council on Disability

### **NCD Medicaid Managed Care Principles**

Ari Ne’eman, Council Member, National Council on Disability

### **U.S. Department of Health and Human Services, Centers for Medicare and Medicaid—**

Barbara Edwards, Director, Disabled & Elderly Health Programs

### **Policy Panel and Discussion,**

**Moderator** Clyde Terry, Council Member, National Council on Disability

### **Panel 1: Putting Consumer Control and Peer Support at the Center of Medicaid Managed Care**

Rebecca Thompson, Progress Center for Independent Living

Suzanne Klug, Advocate and Parent

Dr. Randall Owen, Research Assistant Professor in the Department of Disability and Human Development at the University of Illinois

Christine Wilk, Consumer

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

## **Policy Panel and Discussion**

**Moderator** Ari Ne’eman, Council Member, National Council on Disability

### **Panel 2: Medicaid Managed Care State Updates**

Michael Gelder, Senior Advisor on Health Care to Governor Quinn

Ramon Gardenhire, AIDS Foundation of Chicago

Stephanie Altman, Shriver Center

## **Policy Panel and Discussion**

**Moderator** Gary Blumenthal, Council Member, National Council on Disability

### **Panel 3: Disability Across Sectors: Discussing Managed Care**

Ann Ford, Executive Director, Illinois Centers for Independent Living

Heather O’Donnell, Vice-President for Policy, Thresholds

Tony Paulauski, Executive Director, The Arc of Illinois

## **Policy Panel and Discussion**

**Moderator** Clyde Terry

### **Panel 4: Disability-Informed Managed Care**

Merrill Friedman, Vice-President for Advocacy, Wellpoint

Greg Alexander, CEO, Community Care Alliance of Illinois

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

### **Wrap Up, Facilitated Discussion about Next Steps**

Amber Smock, Director of Advocacy, Access Living

Ellen Piekalkiewicz, Capital Health Strategies and NCD Forum

Facilitator

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**Sacramento, CA—May 7, 2014**

**LOCATION:** Alta Regional Center, 2241 Harvard Street

## **Call to Order, Welcome and Introductions**

Kamilah Martin-Proctor, Co-Vice-Chair, National Council on Disability,  
Medicaid Managed Care Principles

Ari Ne’eman, Council Member, National Council on Disability

MaryBeth Musumeci, Associate Director, Kaiser Family Foundation

### **Panel 1: Federal and State Agencies**

**Moderator** Ari Ne’eman, Council Member

Barbara Edwards, Director, Disabled & Elderly Health Programs

Group, Centers for Medicare and Medicaid Services, U.S. Department  
of Health and Human Service

Edwin Acosta, Equal Opportunity Specialist, DHHS Office for Civil Rights, District  
Margaret Tatar, Chief, Medi-Cal Managed Care Division, California Department of Health Care Services

**Panel 2: Putting Consumer Control and Peer Support**

**Moderator** Clyde Terry, Council Member  
Brenda Premo, Chair, California Olmstead Committee and Associate Professor, Center for Disability Issues and Health Professions, Western University  
Silvia Yee, Disability Rights Education and Defense Fund  
Michele Rousey, Self-Advocate  
Chandra Livingston, Self-Advocate

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

**Panel 3: Legal Protections under Medicaid Managed Care**

**Moderator** Gary Blumenthal, Council Member

Abbi Coursele, Managing Attorney, National Health Law Program  
Amber Cutler, Staff Attorney, Senior Law Center  
Deborah Doctor, Disability Rights California

**Question and Answer**

**Panel 4: Disability-Informed Managed Care**

**Moderator** Clyde Terry  
Teresa Favuzzi, Executive Director, California Foundation for Independent Living  
Lisa Hayes, Director, Molina Disability Services  
Merrill Friedman, Vice-President, Wellpoint

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

**Wrap Up, Facilitated Discussion about Next Steps**

Ellen Piekalkiewicz, Capital Health Strategies and NCD Forum Facilitator

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**New York City, NY—Tuesday, June 3, 2014**

**LOCATION:** Baruch College, The City University of New York (CUNY), William and Anita Newman Conference Center, 151 East 25th Street

### **Call to Order, Welcome and Introductions**

William Ebenstein, Ph.D., University Dean for Health and Human Services, CUNY  
Kamilah Martin-Proctor, Co-Vice-Chair, National Council on Disability

### **NCD Medicaid Managed Care Principles**

Ari Ne'eman, Council Member, National Council on Disability  
MaryBeth Musumeci, Associate Director, Kaiser Family Foundation

### **Policy Panel and Discussion**

**Moderator** Kamilah Martin-Proctor, National Council on Disability  
Mark Murphy, Disability Rights New York

#### **Panel 1: Federal Update—Medicaid Managed Care**

Barbara Edwards, Director, Disabled & Elderly Health Programs  
Group, Centers for Medicare and Medicaid Services, U.S. Department  
of Health and Human Services  
Kelly Buckland, Executive Director, National Council on Independent  
Living

### **Policy Panel and Discussion**

**Moderator** Gary Blumenthal, National Council on Disability

#### **Panel 2: Putting Consumer Control and Peer Support at the Center of Medicaid Managed Care**

Mariette Bates, Ph.D, Academic Director, Disability Studies Program,  
School of Professional Studies, CUNY  
Lori Podvesker, Parent; Manhattan Development Disabilities Council;  
Coalition of Action to Reform and Improve Special Education  
Timothy Elliott, Regional Organizer, Self-Advocacy Association

### **Policy Panel and Discussion**

**Moderator** Stephanie Orlando, National Council on Disability

#### **Panel 3: Children/Youth, Psychiatric Disabilities and Managed Care**

Paige Pierce, Executive Director of Families Together in New York  
State  
Donna M. Bradbury, Associate Commissioner, Division of Children &  
Family Services, NYS Office of Mental Health  
Mimi Weber, Bureau Director, Division of Child Welfare & Community  
Service, NYS Office of Children and Family Services, YOUTH  
POWER! (NY Statewide Organization) Representative

### **Policy Panel and Discussion**

**Moderator** Clyde Terry, National Council on Disability

#### **Panel 4: Disability-Informed Managed Care**

Marco Damiani, Executive Vice President, YAI Network  
Jennifer Hajj, Sachs Policy Group  
Merrill Friedman, Vice-President, Wellpoint

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

**Wrap Up, Facilitated Discussion about Next Steps/Actions**  
Mark Murphy and Gary Blumenthal

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**Atlanta, GA—Tuesday, October 7, 2014**

**LOCATION:** Shepherd Center, 2020 Peachtree Rd NE

**Call to Order, Welcome and Introductions**

Dr. Gary R. Ulicny, CEO and President, Shepherd Center  
Kamilah Martin-Proctor, Co-Vice-Chair, National Council on Disability

**NCD Medicaid Managed Care Principles**

Ari Ne'eman, Council Member, NCD

**Medicaid Managed Care: National Trends**

Marybeth Musumeci, Associate Director, Kaiser Family Foundation

**Medicaid Managed Care: State Update**

Marcey Alter (*invited*), Deputy Director, Department of Community Health

**Medicaid Managed Care: Federal Update**

Carrie Smith, Deputy Division Director of Managed Care Plans Division, Centers for Medicare and Medicaid

**Panel: Medicaid Managed Care: the Role of Advocates**

**Moderator** Gary Blumenthal, National Council on Disability

Curt Decker, Executive Director, National Disability Rights Network  
Ellyn Jaegar, Director of Public Policy and Advocacy, Mental Health  
America of Georgia

Dave Zilles, Parent Advocate, CARE-M

Melanie McNeil, Long-Term Care Ombudsman, Georgia Department of  
Health and Human Services

**Panel: Medicaid Managed Care: Consumer Protections**

**Moderator** Clyde Terry, National Council on Disability

Anne Swerlick, Deputy Director, Florida Legal Services

Dawn Afford, Self-Advocate, CARE-M

Ruby Moore, Executive Director, Georgia Advocacy Office

Talley Wells, Director Disability Integration Project, Atlanta Legal Aid  
Society

## **Wrap Up, Facilitated Discussion About Next Steps/Actions**

Kamilah Martin-Proctor, Curt Decker, Ellyn Jaegar

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**Philadelphia, PA—Friday, December 12, 2014**

LOCATION: Liberty Resources, Inc., Wade Blank Rooms

### **Call to Order, Welcome and Introductions**

Thomas Earle, CEO, Liberty Resources, Inc.

Kamilah Martin-Proctor, Co-Vice-Chair, National Council on Disability (NCD)

### **Policy Panel and Discussion**

**Moderator** Ari Ne'eman, NCD

#### **Panel 1: Changes to Medicaid Benefits—Healthy Pennsylvania**

Governor-Elect (*invited*), Wolf Transition Staff Representative

Antoinette Kraus, Executive Director, Pennsylvania Health Access

Stanley Holbrook, Executive Director, Pennsylvania Independent Living Centers

### **Policy Panel and Discussion**

**Moderator** Clyde Terry, National Council on Disability

#### **Panel 2: Federal Update—Medicaid Managed Care**

Carrie Smith, Deputy Division Director of Managed Care Plans

Division, Centers for Medicare and Medicaid

### **NCD Medicaid Managed Care Principles/NCD Recommendations**

Ari Ne'eman, Council Member, National Council on Disability

### **Medicaid Managed Care Trends Across the United States**

MaryBeth Musumeci, Associate Director, Kaiser Family Foundation

### **Policy Panel and Discussion**

**Moderator** Gary Blumenthal, National Council on Disability

#### **Panel 3: Medicaid Managed Care Behavioral Health Care Carve-Out**

Wayne Pendleton, Liberty Resources, Inc.

Walter Davis, Director of Marketing and Community Development,

Wedge Recovery Centers

Sue Walther, Executive Director, Mental Health Association in Pennsylvania

### **Medicaid Managed Care In Jersey—Advice for Pennsylvania Advocates**

Sue Saidel, Disability Rights New Jersey

## **Policy Panel and Discussion**

**Moderator** Kamilah Martin-Proctor, Co-Vice-Chair, National Council on Disability

### **Panel 4: Medicaid Managed Care**

Laval Miller-Wilson, Executive Director, Pennsylvania Law Project  
Jean Searle, Policy Advocate, Disability Rights Network of Pennsylvania  
Dennis Fealty, President, William Penn Human Services  
Kathy Brill, Executive Director, Parent to Parent USA

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**Baton Rouge, LA—Thursday, February 12, 2015**

LOCATION: AARP Louisiana State Office, One American Place, 301 Main Street

## **Call to Order, Welcome and Introductions**

Andrew Muhl, Policy Director, AARP Louisiana  
Kamilah Martin-Proctor, Co-Vice-Chair, National Council on Disability,  
NCD Medicaid Managed Care Principles and NCD Recommendations  
Ari Ne'eman, Council Member, National Council on Disability

## **Policy Panel and Discussion**

**Moderator** Clyde Terry, National Council on Disability

### **Panel 1: Federal Update—Medicaid Managed Care**

Dianne Kayala, Deputy Director of the Division of Managed Care  
Plans, Centers for Medicare and Medicaid Services, U.S. Department  
of Health and Human Services  
Rocky Nichols, Executive Director, Disability Rights Kansas; Board  
President, National Disability Rights Network

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

## **National Health Law Program Recommendations to CMS**

Elizabeth Edwards, Staff Attorney, National Health Law Program

## **Louisiana Medicaid Managed Care—State of the State**

Ruth Kennedy, State Medicaid Director

## **Policy Panel and Discussion**

**Moderator** Clyde Terry, National Council on Disability

### **Panel 2: Louisiana Medicaid Managed Care**

Stephanie Patrick, Advocacy Center, Louisiana  
Sandee Winchell, Developmental Disabilities Council  
Merrill Friedman, Vice-President, Amerigroup

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

## **Policy Panel and Discussion**

**Moderator** Gary Blumenthal, National Council on Disability

### **Panel 3: Having Person-Centered at the Center of Medicaid Managed Care**

Karen Scallan, Certified Parent Support Provider, Special Needs & Parent Support Services of LA

Bambi Polotzola, Parent

Rebecca Ellis, Parent, Northshore Families Helping Families

## **Wrap Up, Facilitated Discussion** about Next Steps/Actions

Rocky Nichols, Gary Blumenthal, and Ellen Piekalkiewicz

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**Austin, TX—Monday, June 15, 2015**

LOCATION: Disability Rights Texas, 2222 West Braker Lane

## **Call to Order, Welcome and Introductions**

Mary Faithful, Executive Director, Disability Rights Texas

Kamilah Martin-Proctor, Co-Vice-Chair, National Council on Disability, NCD Medicaid Managed Care Principles and NCD Recommendations

Ari Ne'eman, Council Member, National Council on Disability

## **Policy Panel and Discussion**

**Moderator** Clyde Terry, National Council on Disability

### **Panel 1: Federal Update—Medicaid Managed Care**

Dianne Kayala, Deputy Director of the Division of Managed Care Plans, Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services

Rocky Nichols, Executive Director, Disability Rights Kansas; Board President, National Disability Rights Network

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

## **Policy Panel and Discussion**

**Moderator** Gary Blumenthal, National Council on Disability

### **Panel 2: Having Person-Centered at the Center of Medicaid Managed Care**

Karen Ranus, Executive Director, NAMI Texas

Susan Garnett, Executive Director and Parent, MHMR of Tarrant County

Catherine Carlton, Parent, MHMRTC of Tarrant County

Elizabeth Tucker, Policy Director and Parent, Every Child Texas

**Texas Medicaid Managed Care Overview**

Gary Jessee, Texas Deputy Commissioner of Medicaid and CHIP

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

**Policy Panel and Discussion**

**Moderator** Ari Ne’eman, National Council on Disability

**Panel 3: Texas Medicaid Managed Care—State of the State**

Daniel and Debbie Wiederhold, Self-Advocate

Susan Murphree, Senior Policy Analyst, Disability Rights Texas

Trey Berndt, Associate Director of Advocacy, AARP Texas

**Policy Panel and Discussion**

**Moderator** Clyde Terry, National Council on Disability

**Panel 4: Medicaid Managed Care Best Practices**

Don Langer, President, United Healthcare

Merrill Friedman, Vice-President, Amerigroup

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

**Policy Panel and Discussion**

**Moderator** Gary Blumenthal, National Council on Disability

**Panel 5: Medicaid Managed Care—Where We Are? And Where Are We Going?**

Bob Kafka, Executive Director, Texas ADAPT

Bruce Darling, Chief Executive Officer, Center for Disability Rights

**Wrap Up, Facilitated Discussion** about Next Steps/Actions

Ellen Piekalkiewicz and Gary Blumenthal

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**KanCare Public Hearing  
Topeka, KS—Tuesday, July 7, 2015**

**LOCATION:** Old Supreme Court Room, Kansas Statehouse, 300 SW Kansas Avenue,

**Call to Order, Welcome and Introductions**

Kamilah Martin-Proctor, Co-Vice-Chair, National Council on Disability

**NCD Medicaid Managed Care Recommendations, Part I**

Ellen Piekalkiewicz, NCD Contractor, Capital Health Strategies

**Policy Panel and Discussion**

**Moderator** Clyde Terry, National Council on Disability

**Panel: Federal and State Update—Medicaid Managed Care**

Dianne Kayala, Deputy Director of the Division of Managed Care Plans, Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services

Kari Bruffett, Secretary, Kansas Department of Aging and Disability  
Rocky Nichols, Executive Director, Disability Rights Kansas; Board President, National Disability Rights Network

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

**Moderators** Gary Blumenthal and Kamilah Martin-Proctor, National Council on Disability

**Wrap Up, Facilitated Discussion about Next Steps/Actions**

**Moderator** Clyde Terry, National Council on Disability

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**Madison, WI—Monday, August 31, 2015**

**LOCATION:** Wisconsin State Capitol, Room 412 East, 2 East Main Street

**Call to Order, Welcome and Introductions**

Kamilah Martin-Proctor, Co-Vice-Chair, National Council on Disability

**NCD Medicaid Managed Care Principles and NCD Recommendations**

Ari Ne’eman, Council Member, National Council on Disability

**Policy Panel and Discussion**

**Moderator** Clyde Terry, National Council on Disability

**Panel 1: Federal Update—Medicaid Managed Care**

Dianne Kayala, Deputy Director of the Division of Managed Care Plans, Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services

Rocky Nichols, Executive Director, Disability Rights Kansas; Board President, National Disability Rights Network

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

**Policy Panel and Discussion**

**Moderator** Clyde Terry, National Council on Disability

**Panel 2: Best Practices in Integrated Care**

Sue Urban, RN, CDP, Director of Clinical Services TMG

Drew Smith, Director of Research and Data, The Council on Quality and Leadership

Donna McDowell, former Director of the Bureau of Aging & Disability Resources

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

**Wisconsin Medicaid Managed and Long-Term Care Overview**

Brian Shoup, Department of Health Services, Division of Long-Term Care

**Kamilah Martin-Proctor, NCD Council Member, Question and Answer**

**Policy Panel and Discussion**

**Moderator** Gary Blumenthal, National Council on Disability

**Panel 3: Self Direction at the Center of Medicaid Managed Care**

Jessica Nell, Self-Determination Advocate

Merrill Friedman, Vice-President, Amerigroup

Mary Panzer, Former State Legislator

Mitchell Hagopian, Supervising Attorney, Disability Rights Wisconsin; Member, IRIS Advisory Committee

**Gary Blumenthal, NCD Council Member, Question and Answer**

**Policy Panel and Discussion**

**Moderator** Ari Ne'eman, National Council on Disability

**Panel 4: Integrated Employment Under Medicaid Managed Care**

Patrick Young, Self-Advocate

Doug Hunt, Dane County Employment Supports Coordinator

Mary Beth Popchock, Lakeside Curative in Racine County

Mark Hilliker, CEO, Community Care of Central Wisconsin

**Ari Ne'eman, NCD Council Member, Question and Answer**

**Policy Panel and Discussion**

**Moderator** Gary Blumenthal, National Council on Disability

**Panel 5: Medicaid Managed Care—Where We Are? And Where Are We Going?**

Andy Thain, Founder and CEO, AT Home Care

Helen Marks Dicks, Association State Director Advocacy, AARP-Wisconsin

Beth Swedeen, Executive Director, Wisconsin Board for People with Developmental Disabilities and Survival Coalition

**Gary Blumenthal, NCD Council Member, Question and Answer**

**Wrap Up, Facilitated Discussion about Next Steps/Actions**

Ellen Piekalkiewicz and Gary Blumenthal

## Appendix B. NCD Recommendations—HHS/CMS Proposed Rule

On May 26, 2015, for the first time in more than 10 years, HHS/CMS (CMS) issued a notice of proposed rulemaking and released the long awaited proposed rule on Medicaid managed care. The proposed rule discussed in this appendix document was published by CMS in the *Federal Register* from June 1, 2015, through July 27, 2015

NCD used the data and information gathered at the 2014–2015 MMC forums in an analysis of the proposed CMS rule. Some stakeholders consider the proposed rule long overdue, given that most of the provisions governing MMC were drafted in a 2002 regulation. When NCD completed its summary report on the MMC forums at the end of calendar year 2015, no final rule had been issued.

In both vision and scope, the 2015 CMS proposed rule represents a defining moment in the life of Medicaid beneficiaries, including people with disabilities. Among problems for vulnerable populations (including people with disabilities) is that the earlier (pre-2015 proposed rule) provisions reflect an outdated interpretation of what managed Medicaid should and could accomplish for individuals and their families. The proposed rule advances thinking about how to organize and deliver health care for millions of people and how Medicaid-sponsored coverage should integrate with private coverage, in particular, qualified health plans sold in the federal and state health care exchanges. The proposed rule also creates a framework for making managed care work favorably for high-needs populations receiving long-term services and supports (including people with disabilities whose integration into a managed care arrangement is still in a relatively new stage).

The 653-page proposed rule represents the biggest change in Medicaid managed care regulations in more than a decade. It is long overdue, considering that MLTSS activity was considered in its infancy when the CMS rule was last updated.

However, Medicaid managed care enrollment has soared; it is estimated that by the end of 2015, 73 percent of Medicaid beneficiaries will receive services through a managed care plan (Dickson, 2015). Due to the growth of Medicaid, the reach of the Medicaid managed care market into new populations, the emphasis on clinical and financial integration as part of system transformation, and the establishment of Federal Health Exchanges, CMS was moved to re-engineer its managed care rules, which had been designed for somewhat simpler times.

Among the issues worth watching are: (1) whether the proposed rule can solve some matters of access to health care; (2) long-term services and supports; and (3) level of cost saving in contracting out Medicaid to private plan. Cost studies have been more mixed, with no clear consensus emerging as to whether managed long-term care saves money for public purchasers (HHS, 2005). Savings notwithstanding, the budget predictability that comes with capitated payments is appealing to state policymakers as

growing numbers of long-term care consumers place increasing pressure on Medicaid budgets.

A 2013 report to Congress indicates that CMS needed to continue steps to improve federal oversight of rate-setting for Medicaid managed care (GAO, 2013). In 2014, another report disclosed that states were not enforcing their own state requirements to ensure Medicaid patients had enough providers to care for them (HHS OIG, 2014). The report stated that CMS is not doing enough to enforce its own standards. According to the report, CMS uses a checklist to confirm that states have access standards, but the agency does not assess whether these standards are adequate to ensure access to care. CMS had not enforced a requirement that states collect and report encounter data that gives detailed information about services provided to individual Medicaid managed care patients. In a recent report, GAO criticized CMS for lax oversight and inconsistency in tracking how states set managed care plans' rates (GAO, 2015). The tracking was essential to help avoid significant overpayments and to reduce incentives to underserve or deny enrollees' access to needed care.

States are required by the Federal Government to establish quality standards for Medicaid plans and monitor their compliance, but there is no uniformity of process. This has resulted in a patchwork of contract requirements and data collection that experts say makes it difficult to compare states and assess whether patients' health has actually improved.

A study conducted by the Urban Institute (UI) of Medicaid managed care found tremendous variation in the kinds of quality monitoring conducted by states and health plans. The UI researchers revealed that their study also found gaps in federal monitoring: "We saw unevenness in both how the rates are set and in the federal oversight of the state's oversight. The requirements exist, but CMS does not evenly enforce through the regional offices" (Howell et al., 2012).

Requirements for maintaining adequate provider networks, rating setting, performances standards, and data collection were included in the proposed rule, but like actions on other provisions in the proposed rule, CMS mostly punted the task of implementation and enforcement to the states, despite the states' previous lackluster monitoring and enforcement. CMS stated in the proposed rule that the state has the primary responsibility for administering and monitoring the Medicaid managed-care program. It is unclear how financially strapped state Medicaid programs will respond and step up their monitoring and enforcement of Medicaid managed care plans.

Under Medicaid managed care, the Federal Government and states shifted their focus and resources into oversight functions that barely existed in FFS Medicaid. While state and federal monitoring have improved over time, monitoring is not yet at the point of ensuring access and quality. The lack of federal monitoring of state compliance has resulted in managed care programs that fail to meet the needs of enrollees. Despite the potential for improved Medicaid managed care regulations through the proposed rule, the question remains: Will monitoring and enforcement by the states and CMS be adequate? In essence, are the monitoring bodies (CMS and the states) setting performance standards, checking that the monitored entity meets the standards,

providing regular feedback, developing data, and analyzing that data to review outcomes? Adequate and effective monitoring also implies timeliness, allocation of sufficient resources, consistently applied processes and standards, and evidence of improvements over time. As states expand their use of MLTSS programs, they must build upon the experiences of other states that have been the pioneers. Less experienced states will need to consider actions (such as identifying key Medicaid managed care monitoring) and questions (such as what methods are successful in a given social, economic, and political climate and what level of resources will be required). Another challenge is convincing legislators to increase funds for more staff to monitor managed care compared to running the traditional Medicaid insurance program.

Because state and federal oversight is clearly inadequate, NCD has recommended establishing a P&A program to protect the rights of Medicaid beneficiaries. However, the proposed rule makes no mention of a new P&A program. Neither does the rule require states to establish an independent ombudsman, as recommended by NCD, to identify systemic problems in MLTSS programs.

Among the reasons for concern, as commercial risk-based insurers expand outreach to vulnerable populations, are the populations' relatively high levels of health care needs and the potential that these populations could become targets for cost-cutting. Managed care carries the potential for health care coordination to improve that care and to meet the many care needs that vulnerable populations experience. At the same time, commercial managed-care plans' actions to control costs and generate profits for shareholders may conflict with the cost of providing high-quality care. Stakeholders will need to keep vigilant as implementation of the new CMS managed care rule moves forward.

The proposed rule makes a number of changes designed to align Medicaid managed care operating standards with the standards used in other insurance markets. CMS has proposed to modernize the Medicaid managed care regulatory structure to facilitate and support reform of health care delivery and outcomes.

The proposed rule has multiple direct purposes: (1) to improve the accountability of rates paid in the Medicaid managed care program; (2) to ensure beneficiary protections in the areas of provider networks, coverage standards, and treatment of appeals; and (3) to strengthen program integrity safeguards. In so doing, the proposed rule seeks to balance greater regulatory oversight and accountability of both state and industry practices with wider deference to states in how they choose to design managed care and utilize contractors.

Most fundamentally, the new rule would extend a more rigorous regulatory structure to all forms of capitated managed care, whether full-risk MCOs or partially capitated plans. The reforms themselves sweep across a broad landscape. With its proposed rule, CMS has taken a step toward recognizing the true significance of Medicaid managed care as part of the broader health care landscape.

This document concludes with the list below that compares nine NCD recommendations (NCD, 2014) with CMS on how the proposed regulations address the same issues and concerns.

1. **NCD Recommendation:** CMS should fund and direct states to provide adequate funding for an independent ombudsman's office. **CMS Proposed Rule (2015):** The proposed rule does not require states to establish an independent ombudsman to identify systemic problems in MLTSS programs.
2. **NCD Recommendation:** CMS should fund a Medicaid Advisory program within the federally mandated P&A agencies to ensure Medicaid managed care programs at the state level are adequately protecting the rights of consumers. **CMS Proposed Rule (2015):** No mention is made in the proposed rule of establishing a P&A health advocacy program to safeguard the rights of Medicaid beneficiaries.
3. **NCD Recommendation:** CMS regulations and policy guidance must clearly outline Constitutional Due Process principles: recognizing the right to continuation of benefits under Medicaid; clarifying that plans must provide for continued coverage of terminated or interrupted services pending a final appeal decision, regardless of whether an authorization period has expired or not; clarifying that beneficiaries will not be liable for the cost of disputed services should they choose to appeal a service reduction; and tightening the timeframes within which grievance decisions must be provided. **CMS Proposed Rule (2015):** Most capitated, risk-bearing forms of Medicaid managed care—whether full or partial risk—would be expected to offer an internal appeals process with specified time frames, with external appeal to the state Medicaid fair hearing process in the event of an adverse determination. During the appeal, the right on the continued benefits is mandated under the proposed rule.
4. **NCD Recommendation:** CMS must require states to publicize a clear mechanism for monitoring MCO compliance with the Due Process requirements. **CMS Proposed Rule (2015):** The proposed rule would require monitoring to address specific aspects of managed care at a minimum, including administration and management, appeal and grievance systems, claims management, enrollee materials and customer services, finance and medical loss ratios, information systems and encounter reporting, marketing, medical management and utilization management, program integrity and provider network management, quality improvement, long-term services and supports delivery, and other items of the contract as appropriate.
5. **NCD Recommendation:** To facilitate greater state and health plan compliance with the ADA, CMS should convene a disability community workgroup to write a model ADA compliance plan that provides guidance to MCOs. **CMS Proposed Rule (2015):** The proposed rule requires that MLTSS programs would have to be implemented consistent with ADA provisions and the Supreme Court's 1999 decision in *Olmstead v. L.C.*

6. **NCD Recommendation:** CMS must require an MLR. CMS should require that MCOs must spend at least 85 percent of premiums on medical claims and quality improvements. **CMS Proposed Rule (2015):** The proposed rule includes a nationally uniform 85 percent MLR. However, states would be permitted to set a higher MLR, but those currently using a lower standard would be required to update their requirements.
7. **NCD Recommendation:** CMS should prohibit states from carving out or excluding any public or private institutions from the managed care framework and should increase the incentives for community-based care. **CMS Proposed Rule (2015):** The proposed rule does not speak to the issue of institutional carve-ins or carve-outs, although the rule does address services and supports provided to beneficiaries of all ages who have functional limitations and/or chronic illnesses that have the primary purpose of supporting the ability of the beneficiary to live or work in the setting of their choice, which may include the individual's home, a provider-owned or controlled residential setting, a nursing facility, or other institutional setting.
8. **NCD Recommendation:** CMS should require states to ensure that MCOs maintain a maximum ratio of care coordinators to beneficiaries. **CMS Proposed Rule (2015):** With respect to MLTSS, where there are no commonly used access standards, states would be expected to set time and distance rules and to apply the same factors but in the context of care delivered in home- and community-based settings. Standards would have to reflect state consideration of community integration as the ultimate goal of MLTSS and would have to reflect the different needs of the population in community and residential settings.
9. **NCD Recommendation:** CMS should ensure that adequate Medicaid funds are available for supportive employment services for Medicaid managed care beneficiaries with disabilities. **CMS Proposed Rule (2015):** The rule does not make specific mention of supportive employment but does add to the criteria for defining medically necessary services a requirement that the services address the opportunity for an enrollee to have access to the benefits of community living.

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- Howell, E. M., Palmer, A., and Adams, F., Urban Institute, 2012, "Medicaid and CHIP Risk-Based Managed Care in 20 States: Experiences Over the Past Decade and Lessons for the Future," September 7, 2012.
- National Council on Disability, 2014, "Medicaid Managed Care Forums: Part 1 Summary," October 30, 2014.
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- , Office of Inspector General (OIG), 2014, "Access to Care: Provider Availability in Medicaid Managed Care," December 11, 2014.
- U.S. Government Accounting Office (GAO), 2013, "GAO's 2013 High-Risk Update: Medicare and Medicaid," GAO-13-433T: Publicly Released: February 27, 2013.
- , 2015, "Medicaid: Service Utilization Patterns for Beneficiaries in Managed Care," GAO-15-481: Published: May 29, 2015, Released: June 29, 2015.

## Appendix C. Kansas Public Hearing—July 7, 2015

This 2015 public input session followed stakeholder concerns about persistent problems. Primary issues involved the implementation of Medicaid managed care for individuals needing long-term care services and supports in Kansas. NCD conducted its MMC forum two years earlier in Kansas.

### Background

The State of Kansas implemented statewide Medicaid managed care, known as KanCare, in January 2013. The program included adults with physical disabilities and all HCBS waiver participants but excluded people with intellectual and developmental disabilities.

In December 2013, NCD conducted the first of 10 nationwide Medicaid managed care forums in Topeka, Kansas. NCD heard from KanCare consumers, advocates, and state officials on the implementation of KanCare, and the disability community shared their struggles with the implementation, including some individuals facing substantial cuts to necessary care. Based on the testimony received, many unresolved issues surfaced for people with disabilities.

In NCD's December 13, 2013 letter to CMS, the concerns were expressed, especially to the proposed Section 1115 Waiver Amendment by Kansas, which proposed to incorporate long-term services and supports for people with intellectual or developmental disabilities into the State's managed care KanCare program.

NCD informed CMS of the following concerns about KanCare:

- There was inadequate review and consideration of stakeholder concerns by both Kansas and CMS. The start date for inclusion of long-term services and supports into KanCare was January 1, 2014, with public comments open until December 17, 2013. Comments suggested insufficient consideration, response, or interaction between stakeholders impacted by the proposed waiver amendment and CMS, as well as with state officials.
- There was considerable public and stakeholder resistance to the inclusion of I/DD services to KanCare to be indicative of insufficient effort to value the input and considerations of stakeholders and their expertise.
- NCD requested that CMS require Kansas to fulfill all requirements of the current 1915 (c) waiver by: (1) eliminating the so-called "underserved" waiting list and providing all necessary services to the nearly 1,700 Kansans on it; and (2) serving the 9,552 people Kansas has promised to serve in their 1915 (c) waiver application.
- NCD wanted KanCare contractors to demonstrate their ability to address documented delays in payment to existing providers in order to protect providers, particularly the small providers.

Despite NCD's letter of concern and feedback from Kansas stakeholders, CMS approved the 1115 Waiver Amendment to allow Kansas to incorporate long-term services and supports for people with intellectual or developmental disabilities. This change became effective in February 2014.

### **Topeka, KS July 7, 2015 Public Hearing Overview**

The Topeka KanCare public hearing was attended by 50 people (90 percent preregistered), including self-advocates, family members, service providers, state and federal officials, academia, managed care companies, and cross-disability leadership advocacy organizations. The Topeka hearing was held at the historic Supreme Court room at the Kansas Statehouse.

At the beginning of the public hearing, NCD Consultant Ellen Piekalkiewicz briefed attendees about the proposed CMS rule governing Medicaid managed care and stressed that public comment on the rule continue to July 27, 2015. This public comment is extremely important because the proposed provisions will not be made final until public comments are considered and factored in.

Dianne Kayala, Assistant Director, Disabled and Elderly Health Programs, U.S. HHS/ CMS, participated by telephone. Ms. Kayala spoke at length about the proposed CMS rule on Medicaid managed care published by CMS at the beginning of June 2015. The rule brings Medicaid managed care regulations in line with regular Medicaid, Medicare, the ACA, and regulations governing Federal Qualified Health Centers. Several beneficiary protections were included in this rule, including network adequacy standards, capitation payments, enhanced appeals and grievances, continuation of benefits provisions, and compliance with the ADA and *Olmstead* decision. The proposed rule also proposes to streamline the enrollment process, as well as beneficiary support systems, including choice counseling. There are also provisions for care coordination, person-centered planning, and continuity of care, bringing the rule into alignment with guidance issued by CMS in 2013.

Ms. Kayala talked about the proposed rule in terms of allowing Medicaid to pay for institutions of mental disease for people between 22 and 64 years of age for up to 15 days. Currently, such payments for any length of time are not allowed under Medicaid. She also discussed the time frame for public comment, and consideration for the final rule.

Kansas Secretary Kari Bruffett, Department of Aging and Disability Services, largely praised KanCare. She stated that Medicaid was increasing 7.4 percent per year and that growth was unsustainable. The goal of KanCare, she explained, was to achieve a better level of integration between long-term services and supports and physical and behavioral health; and that coordination of care was to increase patient outcomes and achieve greater efficiency. Secretary Bruffett reviewed the KanCare timeline:

- Summer 2011: Medicaid public forums/Web conferences
- November 2011: KanCare announced; RFP released

- January 2012: KanCare concept paper
- June 2012: KanCare contracts signed: statewide
- August 2012: Section 1115 demonstration application
- Summer and Fall 2012: Educational tours across Kansas
- September–October 2012: Readiness reviews
- January 2013: KanCare go-live
- Summer 2013: Public meetings; submission of amendment
- November 2013: I/DD readiness reviews
- February 2014: I/DD long-term services and supports go-live

Secretary Bruffett then outlined some KanCare successes: In just the first year, emergency room usage for HCBS waiver program participants was reduced by 27 percent; primary care utilization increased 31 percent; participants received more dental and vision; and participants had decreased inpatient hospital days.

Rocky Nichols, Executive Director, Kansas Disability Rights Center, presented information showing the following problems with KanCare:

1. Large service reductions for some KanCare members
2. Huge reductions in HCBS waiver capacity and overall enrollment
3. Lack of understanding about the early and periodic screening, diagnostic and treatment program by MCOs
4. Continued improper notices of action
5. Concerns with management of HCBS waiting list
6. People “lost” in the system
  - End of case management as we know it
  - “Death by a million bureaucratic paper cuts”

### **Compilation of Forum Participant Feedback**

NCD heard from KanCare consumers about the implementation of KanCare. The disability community shared their struggles with the implementation of KanCare, including some individuals facing substantial cuts to necessary care. An analysis of all the comments yields five distinct categories of respondent participant comments regarding their experiences with KanCare: provider networks; limitations in covered benefits; transportation; communication; and care coordination.

During the public hearing portion of the event, NCD heard testimony from 15 people. NCD also received written testimony from seven additional people. The following participants testified in person: Finn Bullers, Self-Advocate; Kerry Cosgrove, Parent; Chritz Daley, Self-Advocate; John Grindell, Provider; Marilyn Kubler, Advocate; Jean Hall, University of Kansas; Mike Oxford, Kansas ADAPT; Rosie Cooper, KS Association of Independent Living Centers; Tom Laign, InterHab; Roxanne Hidaka, Targeted Case Manager; Kim Anderson, Johnson County, Health Navigator, Deaf Services; Shirley Thomas, Aging and Disability Center, Wichita; John Green, Parent; Toni Vincent, Self-Advocate; Joan Kelley, Parent. The following people submitted only written testimony: Petra Haron-Marsh, Kansas Association of the Deaf; Carolyn Miller, Parent; Tim Cunningham, Tri-Valley Developmental Services; Lonnie Day, Parent; Lou Ann Colyer, Pittsburg Independent Living Center; Jackie Garnett, Parent; Mitzi McFatrach, Kansas Advocates for Better Care; and Kathleen Brennon, Tri-Valley Developmental Services, Inc.

Collectively, the participants reported that:

- The KanCare structure is more complex and confusing than before.
- Of the person-centered aims of the new model, two stand out as goals that have not been met: increased employment for people with I/DD and a renewal of efforts to meet the needs of people with co-occurring mental illness and developmental disabilities.
- The KanCare Ombudsman program lacks the independent authority to advocate for consumers and take action to resolve issues. It is located within the Kansas Department for Aging and Disability Services, providing only resource and referral services to KanCare members looking for assistance. The data that is collected by the program is very broad-based and does not identify issues of concerns or potential policy changes that would benefit consumers.
- A stated KanCare goal since its inception has been to provide long-term services and supports within the community instead of an institution. KanCare has provided no data that indicates any appreciable movement toward a community rebalance. Barriers include budget constraints and network inadequacy, resulting in this goal not being realized.
- Without adequate and timely data, it is difficult for advocates to affect policies that protect and support KanCare consumers. KanCare offers minimal opportunities for consumer input through a fragmented, inconsistent communications and outreach process.
- Consumers are being subjected to reduced and denied services. Grievances and appeals have been discouraged.
- The state and MCOs are currently renegotiating contracts, and no public comment is being solicited on systems of program improvements.
- There is little oversight of the KanCare system by the state of Kansas or CMS.

- With the massive cuts made to the state budget, there are few individuals within the state who have the knowledge or authority to oversee the KanCare bureaucracy. Therefore, the MCOs have free reign to make their own decisions.
- The system is less efficient and more bureaucratic than before—it used to take less than a week to get someone crisis services; now it takes 21 days just to get an approval. Approvals for all services now take two to three times longer than they did before.
- There are billing issues, and there are no easy fixes because providers are dealing with such big corporations. By the time the right person is found, he or she changes jobs and the process starts all over again.
- Many employees of the MCOs are poorly trained and do not have any knowledge of what it takes to serve individuals with long-term services and supports needs.
- The oversight of KanCare does not include any staff or consumers with expertise to oversee access to KanCare by the Deaf community.
- Managed care companies do not have staff positions specializing in Deaf member services.
- The MCO health care benefit handbooks are not provided in American Sign Language formats.

*“We believe the utilization of medical insurance managed care model does not fit the home- and community-based structure for long-term services and supports. The vast overhaul of the Kansas programmatic approach has not been appropriate or successful, and we do not recommend such a model be employed elsewhere in the country.” Tom Laign, InterHab (Kansas Hearing Participant, July 7, 2015)*

## Endnotes

<sup>1</sup> National Council on Disability, *Analysis and Recommendations for Implementation of Managed Care in Medicaid and Medicare Programs for People with Disabilities*, February 2012, <http://www.ncd.gov/publications/2012/CMSFebruary272012> (accessed December 26, 2015).

<sup>2</sup> National Council on Disability, *Analysis and Recommendations for Implementation of Managed Care in Medicaid and Medicare Programs for People with Disabilities*, February 2012, <http://www.ncd.gov/publications/2012/CMSFebruary272012> (accessed February 1, 2016). National Council on Disability, *Guiding Principles: Successfully Enrolling People with Disabilities in Medicaid Managed Care Plans*, February 2012, <http://ncd.gov/publications/2012/Feb272012> (accessed February 1, 2016).

<sup>3</sup> National Council on Disability, *Medicaid Managed Care for People with Disabilities: Policy and Implementation Considerations for State and Federal Policymakers*, March 2013, <http://www.ncd.gov/publications/2013/20130315> (accessed December 26, 2015).

<sup>4</sup> Jean P. Hall, et al., *Medicaid Managed Care for Beneficiaries with Disabilities*, *Disability and Health Journal*, vol. 8 (2015), pp. 130–135, <https://kuscholarworks.ku.edu/bitstream/handle/1808/16662/DHJO%20January%202015.pdf?sequence=1>.

<sup>5</sup> Medicaid expenditures presented here do not include administrative costs, accounting adjustments, or data for the U.S. territories. Total Medicaid spending including these additional items was \$492.3 billion in FY 2014. Kaiser Family Foundation, Total Medicaid Spending, <http://kff.org/medicaid/state-indicator/total-medicaid-spending/>.

<sup>6</sup> Health and Medicine Policy Research Group (for The Illinois Department on Aging), “The Transition to Medicaid Managed Care in Illinois: An Opportunity for Long-term Services and Supports Systems Change,” July 2013, <http://hmprg.org/assets/root/Long%20Term%20Care/2013/MLTSSReport.pdf>.

<sup>7</sup> Ibid.

<sup>8</sup> *Federal Register*, Volume 80, Issue 104, Regulatory Information AE 2.7: GS 4.107: pp. 30919–31297 (June 1, 2015), <https://www.gpo.gov/fdsys/pkg/FR-2015-06-01/content-detail.html> (accessed December 28, 2015).

<sup>9</sup> Ibid.

<sup>10</sup> U.S. Department of Health and Human Services, Office of Minority Health, *The National CLAS Standards*, 2015, <http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=53>.

<sup>11</sup> National Council on Disability, *Medicaid Managed Care*, 2013.

<sup>12</sup> U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, *Timeline for Developing a Managed Long Term Services and Supports*

(MLTSS) Program, May 2013, <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/downloads/mltss-timeline.pdf> (accessed February 1, 2016).

<sup>13</sup> 42 C.F.R. Title 42, Subchapter C, Medical Assistance Program Subpart A, § 431.12, Medical Care Advisory Committee, p. 26, [http://cfr.regstoday.com/42cfr431.aspx#42\\_CFR\\_431p12](http://cfr.regstoday.com/42cfr431.aspx#42_CFR_431p12) (accessed December 26, 2015).

<sup>14</sup> Alice Dembner, “Putting Consumers First,” Community Catalyst, Inc., November 2012, [http://www.communitycatalyst.org/doc-store/publications/putting\\_consumers\\_first\\_LTSSmanagedcare.pdf](http://www.communitycatalyst.org/doc-store/publications/putting_consumers_first_LTSSmanagedcare.pdf) (accessed December 28, 2015).

<sup>15</sup> Ibid.

<sup>16</sup> Ibid, 14.

<sup>17</sup> Center for Independence of the Disabled New York, “Letter to Mark Kissinger Describing Inadequacy of ADA Appendices of MLTC Plan Contracts with NY State Department of Health” (October 5, 2012), <http://tinyurl.com/CIDNY-MLTC-ADA>.

<sup>18</sup> Government Accountability Office, *Medicaid Program Integrity. Increased Oversight Needed to Ensure Integrity of Growing Managed Care Expenditures*, GAO-14-341, May 19, 2014, <http://www.gao.gov/> (accessed December 23, 2015).

<sup>19</sup> Dembner, “Putting Consumers First: Promising Practices for Medicaid Managed Long-Term Services and Supports,” Community Catalyst, Inc., November 2012.

<sup>20</sup> National Council on Disability, *Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community*, 2015, [http://www.ncd.gov/rawme%20repository/HCBS%20Report\\_INAL.pdf](http://www.ncd.gov/rawme%20repository/HCBS%20Report_INAL.pdf) (accessed December 23, 2015).

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<sup>22</sup> Ibid.

<sup>23</sup> Ibid.

<sup>24</sup> U.S. Department of Health and Human Services, *Federal Policy Guidance 2011*, CMS, <http://www.medicaid.gov/Federal-Policy-Guidance/Federal-Policy-Guidance.html> (accessed December 23, 2015).

<sup>25</sup> Ibid.

<sup>26</sup> Kaiser Family Foundation, “Section 1915 (k) Community First Choice State Plan Option,” 2015, <http://kff.org/medicaid/state-indicator/section-1915k-community-first-choice-state-plan-option/>.

<sup>27</sup> Minnesota Department of Human Services, “Community First Services and Supports,” <http://dashboard.dhs.state.mn.us/measure02-4-1.aspx> (accessed February 2, 2016).

<sup>28</sup> New York Department of Health, “New York State’s Statewide Transition Plan for HCBS Settings,” [http://www.health.ny.gov/health\\_care/medicaid/redesign/docs/state\\_trans\\_plan\\_cms.pdf](http://www.health.ny.gov/health_care/medicaid/redesign/docs/state_trans_plan_cms.pdf) (accessed February 2, 2016).

<sup>29</sup> U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, *Role of Agents, Brokers, and Web-brokers in Health Insurance Marketplaces*, May 2013, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/MLTSS-Summary-Elements.pdf> (accessed December 28, 2015).

<sup>30</sup> Along with the provision of services consistent with ADA protections, stakeholders indicated that community-based long-term services and supports should be delivered in settings that are aligned with requirements for home- and community-based characteristics. The provision of such services should be ways that offer the greatest opportunities for active community and workforce participation. Including this consideration in the planning and oversight of an MLTSS program can ensure progress toward community integration goals.

<sup>31</sup> The “most integrated setting” is defined as “a setting that enables [people] with disabilities to interact with [people without disabilities] to the fullest extent possible,” 28 C.F.R. Pt. 35, App. A (2010).

<sup>32</sup> Ibid.

<sup>33</sup> Community Catalyst, Inc., “Improving Network Adequacy: Ideas for Advocacy Strategies,” February 2014, <http://www.communitycatalyst.org/resources/publications/document/Improving-Network-Adequacy-Ideas-for-Advocacy-Strategies-FINAL-02-18-14.pdf>.

<sup>34</sup> S.B. 760, Texas Legislative Session 84(R), 2015, <http://txlege.texasribune.org/84/bills/SB760/> (accessed February 2, 2016).

<sup>35</sup> Ibid.

<sup>36</sup> U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, *Updates to the §1915 (c) Waiver Instructions and Technical Guide regarding employment and employment related services*, September 16, 2011, <http://downloads.cms.gov/cmsgov/archived-downloads/CMCSBulletins/downloads/CIB-9-16-11.pdf> (accessed December 28, 2015).

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<sup>38</sup> National Health Law Program, “Medicaid Managed Care: Enrollment and Education,” April 1, 2012, <http://www.healthlaw.org/issues/medicaid/managed-care>.

<sup>39</sup> U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services, “Request Managed Care Technical Assistance” webpage, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Managed-Care/Request-Managed-Care-Technical-Assistance.html> (accessed February 3, 2016).

<sup>40</sup> Ibid.

<sup>41</sup> U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, “Medicaid Managed Long Term Services and Supports (MLTSS)” webpage, <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/medicaid-managed-long-term-services-and-supports-mltss.html> (accessed December 28, 2015).

<sup>42</sup> U.S. Department of Health and Human Services, Office of the Inspector General, *State Standards for Access to Care in Medicaid Managed Care*, September 25, 2014, OEI-02-11-00320, at 15-16 (Sept. 2014). <http://oig.hhs.gov/oei/reports/oei-02-11-00320.asp>.

<sup>43</sup> National Senior Citizens Law Center, “Is It Working? Recommendations for Measuring Rebalancing in Dual Eligible Demonstrations and MLTSS Waivers,” [http://dualsdemoadvocacy.org/wp-content/uploads/2014/01/Rebalancing-in-MLTSS-and-Dual-Eligible-Demo\\_01.13.14.pdf](http://dualsdemoadvocacy.org/wp-content/uploads/2014/01/Rebalancing-in-MLTSS-and-Dual-Eligible-Demo_01.13.14.pdf).