

December 20, 2013  
VIA ELECTRONIC MAIL

Medicaid and CHIP Payment and Access Commission (MACPAC)  
comments@macpac.gov

Dear Commissioners,

United Spinal Association is writing to follow up on your recent December 12<sup>th</sup> public meeting held in Washington DC, particularly the presentations and discussions regarding Medicaid managed care (MMC) and long term services and supports (LTSS). Thank you for the opportunity to attend in person and to provide comments. Based on presentations and discussion during the public meeting, United Spinal urges you to consider the following:

- During your review of managed care program oversight, consider interviewing organizations that advocate for and by consumers, as well as managed care organizations (MCOs), oversight committees and state agencies.
- In future managed care research, examine how all supports and services, including employment, housing and transportation supports, as well as waiver waiting lists, are affected by a transition to managed care.
- Examine how state agencies and MCOs define medical necessity before and after a managed care program is implemented.
- In future LTSS research, consider quality measures that are being used to compare and evaluate programs for people with disabilities, including those that highlight the importance of consumer-direction, satisfaction and independence.
- A successful LTSS program provides the services and supports needed for consumers to live their lives to the fullest.

Founded in 1946 by paralyzed veterans, United Spinal Association is the largest disability-led nonprofit organization serving and representing the interests of more than a million Americans living with spinal cord injuries and disorders (SCI/D). It has approximately 40,000 members in all 50 states and reaches out to these individuals through 42 chapters and 200 support groups. Throughout its history, United Spinal Association has dedicated its energy, and programs, to improving the quality of life for these Americans of all ages and advancing their independence. Many of our members rely on Medicaid LTSS for access to vital services, including: personal care attendants, wheelchairs and other assistive technology, employment, housing and transportation supports.

*Interview Consumer Advocacy Organizations:* Regarding MMC, the Commission indicated that it will conduct an in-depth review of MMC oversight activities. Review will include interviews with CMS staff, state agencies, and MCOs. Please consider interviewing organizations that advocate for and by consumers as well. Protection and Advocacy agencies (P&As) and local centers for independent living (CILs) are both respected and government mandated organizations. In addition, you may consider interviewing members of the National Council on Disability (NCD). NCD recently held a quarterly hearing in Topeka, Kansas, the first of four cities they plan to visit to gather information about MMC.

Consumer advocacy organizations could provide a consumer voice to questions of whether managed care programs are consumer directed; and whether they are providing consistent, quality services, and access to a fair appeals and complaints process. Without outreach to consumers the review is likely to miss crucial aspects of any managed care program, including: whether consumers are given sufficient notice regarding changes in levels of care or providers; the response rate and satisfaction levels with the ombudsman; if support services such as employment, transportation, housing, and assistive technology supports continue to be provided; and whether there are improvements in the system after issues have been identified.

*Recommend Resources for Oversight:* In addition, the Commission indicated that attention should be paid to the need for sufficient resources for oversight. United Spinal agrees and applauds this suggestion. Independent ombudsman programs whose missions are to support consumers are crucial.

*How MLTSS Impacts the Broad Range of Services and Supports, Waiting Lists, Medical Necessity:* Commission staff indicated that managed long term services and supports (MLTSS) would be explored in future reports. United Spinal urges you to consider a broad exploration, examining how all supports and services, including employment, housing and transportation supports, may be affected by a transition to managed care. Please consider, also, addressing the effects MMC programs may have on waiting lists for home and community based waiver programs, and how state agencies and MCOs define medical necessity before and after a managed care program is implemented.

*MLTSS Principles:* In addition, as you know, CMS has provided key elements to a successful managed care program.<sup>i</sup> Please consider reviewing principles and recommendations for effective managed care programs put forth by the Consortium for Citizens with Disabilities, and the National Disability Leadership Alliance.<sup>ii,iii</sup>

*LTSS and home and community based services (HCBS) Quality Measures:* United Spinal thanks the Commission for the attention paid to LTSS. The Commission indicated that there are a lack of quality measures that can be used to compare and evaluate LTSS programs more fully. United Spinal, in coalition with disability and aging organizations, advocates for increased funding for LTSS and HCBS quality measures that highlight the importance of consumer-direction, satisfaction and independence. We are particularly excited about the National Association of States United for Aging and Disability National Core Indicators Aging and Disability (NCI-AD) pilot project that will apply the respected nationwide-NCI survey, traditionally used to measure programs for the Intellectual and Developmental Disability community, to services provided to the aging and disability community.<sup>iv</sup> In addition, we lift up the Council on Quality Leadership's Performance Outcome Measures that identify consumer identity and experiences, daily life, and goals, that may be used by MCOs or state agencies.<sup>v</sup>

We are encouraged by the National Quality Forum's identification of measure gaps to CMS including: goal-directed, person-centered care planning and implementation; the beneficiary sense of control/autonomy/self-determination; community integration; and optimal functioning.<sup>vi</sup> We would hope that access to employment, housing, transportation, timely and appropriate care, and overall satisfaction could be addressed in the future.

*Durable Medical Equipment:* Regarding the Commission's concern regarding waste, fraud and abuse in the durable medical equipment industry; United Spinal acknowledges the need to address fraud, as states face budget shortages. However, while a minority of providers may abuse the system, individuals with disabilities face limited access to the durable medical equipment and related supplies and service they need every day. Many of our members lack access to customized wheelchairs that could prevent pressure sores and potential hospitalizations and allow them to lead more active lives. What with

Healthcare Common Procedure Coding System changes recently eliminating the K0009 wheelchair code, the November release of the final rule of *CMS-1526-F Medicare Program; End-Stage Renal Disease Prospective Payment System, Quality Incentive Program, and Durable Medical Equipment, Prosthetics, Orthotics, and Supplies* (converting durable medical equipment items from the routinely purchased code to capped rental items) and the expansion of the Centers for Medicare and Medicaid Services' bidding program; United Spinal is very concerned about beneficiary access to medically required equipment and related service and repairs, particularly to wheelchairs which can take several months to complete.<sup>vii</sup>

*Definitions of Successful LTSS Programs:* Finally, the Commission indicated that future reports may examine what defines success for LTSS. For United Spinal's members a successful LTSS program provides the supports the consumer needs to live their dreams, as integrated members of society, in the setting they choose, with access to employment, transportation, and full community participation. In essence, LTSS can be the key to allowing consumers to life their lives to the fullest. Consider reviewing LTSS principles, developed by CCD and the Leadership Council of Aging Organizations (LCAO), intended to provide a framework for focusing attention and generating solutions to LTSS challenges.<sup>viii</sup>

Thank you, again, for the opportunity to attend the December 12<sup>th</sup> public meeting and for the work you do that highlights the vital role that Medicaid plays in the lives of so many Americans. United Spinal Association will continue to advocate on behalf of our members and for quality MMC programs and LTSS. We look forward to the March Commission report and to engaging in the future. Should you have any questions, please contact United Spinal Association's Senior Policy Associate, Carol Tyson at (202) 556-2076 ext 7104 or at [ctyson@unitedspinal.org](mailto:ctyson@unitedspinal.org).

Sincerely,

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Vice President, Government Relations  
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Enclosures

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<sup>i</sup> Centers for Medicare & Medicaid Services (CMS). (20 May 2013). Guidance to States using 1115 Demonstrations or 1915(c) Waivers for Managed Long Term Services and Supports Programs. <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/1115-and-1915b-MLTSS-guidance.pdf>.

<sup>ii</sup> Consortium for Citizens with Disabilities Endorsing Organizations (11 May 2012). Principles and Recommendations for Transitioning People with Disabilities into Medicaid Managed Care. [http://www.c-c-d.org/fichiers/CCD\\_Medicaid\\_Managed\\_Care\\_Principles.pdf](http://www.c-c-d.org/fichiers/CCD_Medicaid_Managed_Care_Principles.pdf)

<sup>iii</sup> National Disability Leadership Alliance (March 2012). Principles for Providing Coordinated Quality Health Care in Medicaid Managed Care Programs for those /living with Significant Disabilities. <http://www.disabilityleadership.org/files/NDLA%20Principles%20For%20Medicaid%20Managed%20Care%20%28March%202012%29%20--%20%20Final.PDF>

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<sup>iv</sup> Refer to <http://www.nasud.org/initiatives/national-core-indicators-aging-and-disabilities> for more on the NCI-AD project.

<sup>v</sup> Refer to <http://www.thecouncil.org/index.aspx> for more on Performance Outcome Measures.

<sup>vi</sup> National Quality Forum (12 July 2012). Summary Memo: Family of Measures for Dual Eligible Beneficiaries: Preliminary Findings from the MAP Dual Eligible Beneficiaries Workgroup. <http://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=73326>

<sup>vii</sup> United Spinal Association letters to CMS, RE: “CMS-1526-P, Medicare Program; End-Stage Renal Disease Prospective Payment System, Quality Incentive Program, and Durable Medical Equipment, Prosthetics, Orthotics, and Supplies” (August 30, 2013) and “Wheelchair Repair Within and Outside the Bidding Program,” (December 16, 2013).

<sup>viii</sup> Consortium for Citizens with Disabilities and the Leadership Council of Aging Organizations (28 August 2013) Principles for Long Term Services and Supports. <http://www.c-c-d.org/fichiers/LCAO-CCD-Principles-for-LTSS-Final.pdf>