March 23, 2020

Seema Verma, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-2324-NC
P.O. Box 8016
Baltimore, MD 21244–8010

RE: Coordinating Care from Out-of-State Providers for Medicaid-Eligible Children with Medically Complex Conditions
CMS–2324–NC; RIN 0938–ZB57

Dear Administrator Verma,

The National Health Law Program appreciates the opportunity to submit comments regarding the Request for Information on Coordinating Care from Out-of-State Providers for Medicaid Eligible Children with Medically Complex Conditions. The National Health Law Program (NHeLP) protects and advances the health rights of low-income and underserved individuals and families by advocating, educating, and litigating at the federal and state level.

Along with much of the country, NHeLP's work has shifted dramatically over the past several weeks to focus on urgent issues caused by the COVID-19 pandemic. Given the national emergency caused by the novel coronavirus, NHeLP is unable to provide a complete response to this Request for Information at this time, and our comments below address only a few discrete topics. We ask that you extend the public comment period of this Request for Information until after the federal declaration of a

national emergency has passed, so that our organization and other stakeholders— including the families of children with medical complexity— can have the opportunity to provide comprehensive and meaningful comments on this important issue.

Below are comments on two specific topics relevant to this Request for Information: access to durable medical equipment for children with medical complexity while out of state, and the adequacy of community-based services.

Durable Medical Equipment

Children with medical complexity should be able to participate in all aspects of family life, including travel out-of-state to visit family, take vacations, or participate in school trips. Many children with medical complexity use durable medical equipment and supplies, and state Medicaid programs should ensure systems are in place so that children have adequate access to durable medical equipment and supplies when out-of-state.

As with any piece of complex technology, equipment like ventilators and enteral nutrition pumps can malfunction, and when they do, they often must be immediately repaired or replaced to prevent serious medical complications or hospitalization. Moreover, items like wheelchairs are frequently damaged by air travel, which can impair mobility and lead to medical complications.[1] For children that use heavy medical supplies (for example, enteral formula), it can also be difficult for families to physically transport the quantity of supplies needed for out-of-state travel.[2]

Presently, if a child's DME malfunctions while out-of-state, families face significant delays obtaining the required prior authorization and navigating other administrative barriers to obtain equipment repairs or replacements. This delay can pose risks to the child's health. States should develop clear, streamlined processes for children with complex needs who need their

[1] U.S. Department of Transportation, *Air Travel Consumer Report* 40 (Feb. 2020), https://www.transportation.gov/sites/dot.gov/files/2020-02/February%202020%20ATCR.pdf; Jayme Fraser, New Federal Requirements Show Airlines Damage Thousands of Wheelchairs Each Year, USA TODAY NETWORK, Nov. 22 2019, https://www.usatoday.com/story/news/nation/2019/11/22/airlines-department-transportation-report-damage-wheelchairs/4270695002/.
[2] Feeding Tube Awareness Foundation, Traveling, https://www.feedingtubeawareness.org/navigating-life/on-the-go/traveling/ (last visited Mar. 6, 2020).

DME replaced or repaired while out-of-state, and should resolve any barriers to obtaining equipment in an expedited fashion.

For example, states should have mechanisms to rapidly authorize replacement equipment or repairs from out-of-state durable medical equipment companies, and to enroll the providers on an expedited basis. Systems should be in place to help families identify DME providers while traveling and navigate the process of obtaining replacement parts or equipment. In certain cases, states should also provide the family with back-up essential durable medical equipment, if the time it would take to authorize and conduct repair or replacement if equipment malfunctions while out-of-state might jeopardize the child's health. Additionally, for items that do not need urgent replacement, families should also have the option of having their existing home care company ship replacement durable medical equipment to the family while out-of-state. Moreover, if the family prefers to minimize the difficulties of transporting heavy and bulky items, the family's existing home care company should be permitted to ship supplies like enteral formula to a family's out-of-state destination.

Community-Based Services

While it is essential that children with medical complexity are able to access out-of-state care where necessary, it is equally important that children with medical complexity can receive services they need in their own communities via community-based services. Significant evidence shows that with the provision of adequate community-based services, youth with significant mental health needs have better outcomes in home and community-based settings than in institutions.[3] However, many states still report significant numbers of children with mental health conditions served in out-of-state residential treatment facilities, rather than in the community.[4]

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[3] *See, e.g.,* SAMHSA and Nat'l Inst. of Mental Health, *Mental Health: A Report of the Surgeon General* 168 (1999), https://www.surgeongeneral.gov/library/reports/index.html; Joint CMCS and SAMHSA Informational Bulletin, *Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions* (May 7, 2013), https://www.medicaid.gov/sites/default/files/federal-policy-guidance/downloads/CIB-05-07-2013.pdf; SAMHSA, *The Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances Program, Report to Congress* (2015), https://www.samhsa.gov/sites/default/files/programs_campaigns/nitt-ta/2015-report-to-congress.pdf.

[4] *See, e.g.* State of Nevada Governor's Finance Office Division of Internal Audits, *Audit Report: Department of Health and Human Services, Division of Child and Family Services, Child Mental Health Services* 8 (2016),

Demand for residential services, including placement in out-of-state facilities, is all too often driven by a lack of appropriate community-based treatment. However, states have legal obligations to provide appropriate intensive mental health services to children in the community. Under Medicaid's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit, states must provide and arrange for a broad range of services necessary to meet children's behavioral health needs.[5] Courts have found that a lack of intensive community-based mental health services can violate EPSDT, including in a case that involved a child with multiple out-of-state placements.[6] Further, the Americans with Disabilities Act integration mandate requires states to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[7] Further, the Supreme Court has determined that systemic failures to develop an adequate array of community-based services, resulting in unnecessary and unwanted residential and institutional placements, violate this mandate.[8]

In addition to improving outcomes and meeting states' legal obligations, coordinated community-based services and supports for children with mental health needs can reduce the number of children in out-of-state residential treatment.[9] States should ensure intensive community-based mental health services, such as intensive care coordination, crisis services,

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http://budget.nv.gov/uploadedFiles/budgetnvgov/content/IAudits/About/AuditRpts/16-08%20dhhs%20mental%20health.pdf; Montana Dep't of Public Health and Human Services Children's Mental Health Bureau, *Report to the Montana Legislature: Required Out-of-State Placement Monitoring Report* (June 2018), https://leg.mt.gov/content/Committees/Interim/2017-2018/Children-Family/Meetings/June-2018/june2018-out-of-state-placement-report.pdf; Maine Dep't of Health And Human Services, Office of Child and Family Services, *Children's Behavioral Health Services Assessment Final Report* 36 (Dec. 2018), https://www.maine.gov/dhhs/ocfs/cbhs/documents/ME-OCFS-CBHS-Assessment-Final-Report.pdf.

[5] 42 U.S.C. § 1396a(a)(43); *see also* 42 U.S.C. §§ 1396a(a)(10)(A); 1396d(a)(4)(B); 1396d(r).

[6] *Rosie D. v. Romney*, 410 F. Supp. 2d 18, 30 (D. Mass. 2006).

[7] 28 C.F.R. § 35.130(d).

[8] *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 605-606 (1999).

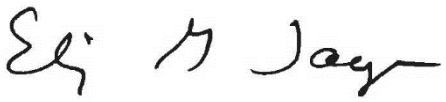
[9] *E.g.* New Jersey Department of Children and Families, *Promising Path to Success: System of Care Expansion and Sustainability Grant* 2 (2015), https://www.nj.gov/dcf/documents/notices/PromisingPath.to.Success-CSOC.Expansion.and.SustainabilitySAMHSA.Grant.pdf; Beth A. Stroul & Robert M. Friedman, *Effective Strategies for Expanding the System of Care Approach: A Report on the Study of Strategies for Expanding Systems of Care* 28 (2011), https://gucchd.georgetown.edu/products/SOC%20Expansion%20Study%20Report%20Final.pdf; John VanDenBerg et al., *History of the Wraparound Process* 3 (2011), https://nwi.pdx.edu/NWI-book/Chapters/VanDenBerg-1.3-(history-of-wraparound).pdf.

intensive home based services, and therapeutic foster care, are provided to all Medicaid-eligible children for whom they are medically necessary.[10] Out-of-state care must not be a substitute for adequate community-based services.

Conclusion

Thank you for the opportunity to submit comments regarding this this Request for Information. As noted above, we request that you extend the comment period until after the national emergency declaration regarding COVID-19 has ended, to permit more complete public comments from NHeLP and other stakeholders. If you have any questions regarding our comments, please contact Hannah Eichner (eichner@healthlaw.org) or Jennifer Lav (lav@healthlaw.org).

Sincerely,



Elizabeth G. Taylor
Executive Director

[10] Kimberly Lewis & Jennifer Lav, National Health Law Prog., *Children's Mental Health Services: The Right to Community Based Care* 10-20 (2018), https://healthlaw.org/resource/childrens-mental-health-services-the-right-to-community-based-care/.