



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

June 3, 2020

Administrator Seema Verma
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-2406-P
P.O. Box 8016
Baltimore, MD 21244-8016

We, the undersigned members of the Consortium for Citizens with Disabilities (CCD) task forces on Health, Education, Long-Term Services and Supports, and Rights, appreciate the opportunity to comment on this Request for Information.

CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

Introduction

We strongly support CMS' efforts to provide high quality and appropriate care for children with medically complex conditions. At times, children must seek care outside of their home state, especially specialty services and specific acute care services like surgeries. The nature of the state-based Medicaid program has created challenges for children with disabilities to get the care they need if it can only be provided outside of their home state. We appreciate CMS taking action to address this issue.

Beyond necessary acute care episodes, children should spend most of their times growing up in their homes, communities, and local schools and with their families. We urge CMS to ensure that implementation of the ACE Kids Act complies with the Olmstead decision and the Individuals with Disabilities Education Act. The Enhanced Pediatric Health Home State Plan Option should be designed to facilitate the provision of needed care followed by the seamless return to children's local communities. Our recommendations are focused on policies that would ensure children with disabilities are served locally to the maximum extent possible and can access out-of-state care seamlessly when needed.

Community Living

While it is essential that children be able to access out-of-state care where necessary, it is equally important that out-of-state facilities do not replace quality community-based services. For example, many states report significant numbers of children with mental health conditions served in out-of-state

residential treatment facilities.¹ However, significant evidence shows that, with the provision of adequate services, youth with disabilities have better outcomes in home and community-based settings.² A child's medically complex conditions may include one or more mental health conditions. Children should have their mental health needs met in addition to their physical health needs.

Demand for residential services, including placement in out-of-state psychiatric residential treatment facilities, nursing facilities, and intermediate care facilities for individuals with developmental disabilities, are all too often driven by a lack of appropriate community-based treatment. However, states have legal obligations to provide appropriate intensive 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 needs.³ For example, 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.⁴ 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."⁵ Systemic failures to develop an adequate array of community-based services, resulting in unnecessary and unwanted residential and institutional placements, violate this mandate.⁶

In addition to improving outcomes and meeting states' legal obligations, coordinated community-based services and supports for children can reduce the number of children in out-of-state residential treatment.⁷ For example, states should ensure that intensive community-based mental health services,

¹ 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), <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>.

² See, e.g., Sandra Friedman, Kenneth Norwood, and AAP Council on Children with Disabilities, *Out-of-Home Placement for Children and Adolescents With Disabilities—Addendum: Care Options for Children and Adolescents With Disabilities and Medical Complexity* 138 *Pediatrics* (2016), <https://doi.org/10.1542/peds.2016-3216>; 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>.

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

⁴ *Rosie D. v. Romney*, 410 F. Supp. 2d 18, 30 (D. Mass. 2006).

⁵ 28 C.F.R. § 35.130(d).

⁶ *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 605-606 (1999).

⁷ 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](https://nwi.pdx.edu/NWI-book/Chapters/VanDenBerg-1.3-(history-of-wraparound).pdf).

such as intensive care coordination, crisis services, intensive home-based services, and therapeutic foster care, are provided to all Medicaid-eligible children for whom they are medically necessary.⁸ Out-of-state care must not be a substitute for adequate community-based services.

Navigation

We urge CMS to include family navigation in the new program. One of the major barriers to accessing or navigating care is the time and effort required to research and identify available providers to provide care for the child. Many provider directories contain inaccurate information and are out-of-date as soon as they're published. This results in families being unaware of providers available in their home state and increases the difficulty of locating out-of-state providers. This is a particularly significant barrier for children in families who may not have access to the internet or digital information, and children in families who speak a primary language other than English. Traditional methods of sharing information with caregivers, such as the use of print or web materials, may be inaccessible for many families. Culturally appropriate, family-centered navigator systems have much greater success in ensuring that families with various needs are able to receive information and thus find the most appropriate care for their children.

Some large hospital systems provide family navigators that assist in locating providers that will see a child after discharge. These staff will provide this navigation for families who are coming from out-of-state to the clinical center to receive care, as well as for families that are leaving the clinical center and will be returning to their home state to continue treatment. We strongly recommend that your guidance encourages states to develop family navigator functions as part of any Enhanced Pediatric Health Home State Plan Option. Such a navigation function will help families identify in-state and out-of-state providers and assist in transition back to their home community.

Referrals

Successful referrals between providers of children with medically complex conditions rely on provider-to-provider consultation. Treating clinicians must consult with receiving providers in order to relay timely and critical information related to the current status of the child's health and treatment plan. This provider-to-provider consultation is often not a reimbursable service under Medicaid, and as a result, clinicians must provide this service on their own time. This reduces the likelihood that all relevant specialty providers will participate in consultation with the transferring provider. The lack of provider consultation about a specific child's history, progress and current status compromises the quality of out-of-state care as well as a successful transition to care at home. We recommend that your guidance encourage states to include coverage for clinical consultation, potentially through methods such as reimbursement for interprofessional telephone/internet consultation codes, as part of the Enhanced Pediatric Health Home State Plan Option.

Network Adequacy

Network adequacy has long been a problem for children enrolled in Medicaid. The Medicaid and CHIP Payment and Access Commission (MACPAC) found that, compared to children with private insurance,

⁸ Kimberly Lewis & Jennifer Lav, National Health Law Program, *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/>.

children on Medicaid faced problems accessing care, including the inability to find a provider who will accept their insurance, the inability to obtain a timely appointment, and the inability to obtain a referral to a specialist or otherwise obtain specialist care.⁹ Inadequate networks increase the likelihood that children on Medicaid will need to seek care out-of-state. CMS should enhance network adequacy requirements and ensure that states are in full compliance with the requirements that already exist, to reduce the use of out-of-state care when possible.

Durable Medical Equipment and Medical Supplies

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,¹⁰ which can impair mobility and lead to medical complications.¹¹ For children that use enteral formula or other heavy or bulky medical supplies, it can also be difficult for families to physically transport the quantity of supplies needed for out-of-state travel.¹²

Presently, if a child's durable medical equipment (DME) malfunctions while out-of-state, families may 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 DME replaced or repaired while out-of-state, and should resolve any barriers to obtaining equipment in an expedited fashion. While addressing the provision of care across state lines, CMS should address these issues in order to facilitate greater community participation for children with disabilities.

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. In certain cases, states should also provide the family with back-up pieces of essential DME, 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

⁹ Medicaid and CHIP Payment and Access Commission, Medicaid Access in Brief: Children's Difficulties in Obtaining Medical Care, (June 2016), <https://www.macpac.gov/wp-content/uploads/2016/06/Childrens-Difficulties-in-Obtaining-Medical-Care.pdf>

¹⁰ 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>.

¹¹ 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/>.

¹² Feeding Tube Awareness Foundation, Traveling, (last visited Mar. 6, 2020) <https://www.feedingtubeawareness.org/navigating-life/on-the-go/traveling/>.

replacement DME 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.

Provider Enrollment

One of the barriers to accessing care out-of-state is provider enrollment in a beneficiary's home state Medicaid program. States should generally honor provider enrollment in other states' Medicaid programs, or accept Medicare enrollment; an out-of-state provider should not be required to enroll as a provider in another state if the provider files more than a set number of claims in a 180-day period, as is currently required.¹³ (The "Accelerating Kids' Access to Care Act," H.R. 5900, would enable an out-of-state provider meeting specified requirements to enroll as a provider in another state's plan without additional screening requirements.) Exceptions to this general rule should exist, however, when it is necessary to ensure the health and safety of the child. For example, a state with state-law limits on restraint and seclusion that are more protective than federal law may wish to condition psychiatric residential treatment facility (PRTF) provider enrollment upon an agreement that the receiving PRTF will abide by the sending state's higher standard.

Telehealth

The COVID-19 crisis has upended health care delivery in the US and transitioned many practices to telehealth nearly overnight. Some providers, beneficiaries, and families report a desire to retain the use of telehealth for certain services after the pandemic. While not an adequate replacement for all health care services, many services can be provided by telehealth well into the future and past this public health emergency. CMS should allow for telehealth services to be provided across state lines, especially as part of the new Enhanced Pediatric Health Home State Plan Option. This would significantly reduce the burden on families and potentially improve clinical outcomes by increasing access to providers who specialize in a child's medical condition.

Thank you for the opportunity to provide input as CMS builds this new program. Please reach out to Rachel Patterson at rpatterson@efa.org with any questions.

Sincerely,

American Academy of Physical Medicine & Rehabilitation
American Association on Health and Disability
American Association on Intellectual and Developmental Disabilities
American Dance Therapy Association
American Music Therapy Association
American Occupational Therapy Association (AOTA)
American Physical Therapy Association
American Therapeutic Recreation Association

¹³ Pursuant to the Medicaid Provider Enrollment Compendium (updated 7/24/2018), a state may not pay a claim unless it represents either – (1) A single instance of care furnished over a 180 day period, or (2) Multiple instances of care furnished to a single participant, over a 180 day period. For any instances of care that exceed the thresholds above, the SMA must enroll the furnishing provider in the state Medicaid plan for subsequent claims to be FFP-eligible.

Autistic Self Advocacy Network
Brain Injury Association of America
Center for Public Representation
CommunicationFIRST
Council of Administrators of Special Education
Easterseals
Epilepsy Foundation
National Association of Councils on Developmental Disabilities
National Association of State Head Injury Administrators
National Health Law Program
Tash
The Arc of the United States