



May 7, 2018

Zeke Smith, Chair
Oregon Health Policy Board

Dear Mr. Smith and Members of the Oregon Health Policy Board:

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) is Oregon’s Title V public health agency for children and youth with special health care needs. Children and youth with special health care needs (CYSHCN) are those “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.”¹ OCCYSHN works to improve the health, development, and well-being of Oregon’s CYSHCN population.

About one in five Oregon children has a special health care need. Recent estimates suggest that more than one-third of Oregon CYSHCN under the age of 18 have public health insurance.² To address the needs of the substantial population of Oregon CYSHCN, we offer the following recommendations for the Oregon Health Authority’s forthcoming contracts with Coordinated Care Coordination Organizations:

1. To improve integration of behavioral and primary medical care, and to ensure access to behavioral health services:
 - a. “Increase statewide investments in integrated primary care and community-based preventive behavioral health and early childhood social-emotional development programs, including home visiting programs. It is critical to ensure sustainable payment levels for integrated behavioral health services and to support a skilled, competent, and effective workforce.”³
 - b. Eliminate mental health carve-out models for primary care practices providing integrated health care.”³
 - c. Require that CCOs “adequately cover a basic package of preventive services via an alternative payment mechanism for integrated patient-centered primary care homes.”³
 - d. Include provisions to provide payment for alternative approaches to providing behavioral health services, including tele-health approaches, to mitigate some of the impact of provider shortages.
2. To improve cross-sector coordination of care, provide payment to primary care providers, or their care coordination staff, for participating in the development of shared plans of care, with community partners including public health, mental health, and education systems.
3. Require CCOs to develop and support alternative payment methods for CYSHCN to support team-based cross-systems care coordination and/or coordination between pediatric and adult providers when a young adult with special health care needs is ready transition from pediatrics to the adult system of health care. Cross-systems care coordination includes health, education, and community service systems.
4. Partner with CCOs to establish a standard for pediatric care coordination. We recommend the *Standards for Systems of Care for Children and Youth with Special Health Care Needs*.⁴ Standards

¹ McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P.W., et al. (1998). A new definition of children with special health care needs. *Pediatrics*, 102(1), 137-140.

² <http://childhealthdata.org/browse/survey/results?q=4828&r=39>

³ *Improving Access to Behavioral Health Care for Children, Adolescents, and Families: Solutions for Advancing Behavioral Health Integration at Primary Care Practices in Oregon*, page 3.

and processes that work for CYSHCN work for all children on the community. We specifically recommend highlighting these components of the standards:

- a. Care coordination integrates community-based services and mental, oral, and physical health.
 - b. Care coordinators serve as members of the child’s health team, have ongoing relationships with the families and other child health team members, provide appropriate resources to align with the health literacy level, primary language, and culture of the CYSHCN and family, assist in managing care transitions across settings and developmental stages, and assist in managing care transitions across settings and developmental stages.
 - c. Care coordination centers around a plan of care that is jointly developed, shared, and implemented among the child or youth, their family, members of the child health care team, and others that are involved in their health and well-being.
5. Require in-network payment rates for specialty care when there is no specialist within the CCO’s network. For example, consider a child with congenital heart disease who lives in Yamhill County. The child needs a pediatric dentist who can administer anesthesia to a child with a heart condition, and such a specialist is only available in Salem. The CCO should pay the Salem provider at in-network rates. Ensuring equitable payment for services is necessary to ensure that families of CYSHCN have access to necessary care across the state.
6. Require CCOs make clear both the CPT codes that are payable, and the documentation needed to support that payment in a timely manner. OCCYSHN stakeholders describe extensive back-and-forth regarding payment from CCOs to providers. This wastes professional time, and delays necessary care for patients. For example, many families report difficulty getting necessary Durable Medical Equipment (DME). Their physicians and allied health therapists have to resubmit requests for authorization after repeated denials. Similarly, physicians working with Community Connections Network (CCN) teams reported trouble being paid for established and approved codes. Repeated communication with CCOs becomes almost the norm. Many have reported giving up, as the level of effort becomes too great.
- a. We perceive that an unintended consequence of removing the exclusions list is increased back-and-forth between family/provider and CCO. Families need to know quickly if their child’s DME is covered by their health insurance, so they can pursue other avenues for funding, like DD services. Ideally, a clear decision tree would show care coordinators and families of CYSHCN who are eligible for DD Services when the CCO will pay for DME, and when DD Services will pay.
7. Assemble a list of adult health care providers who will accept a CYSHCN as they transition from pediatric to adult health care, including the providers’ sub-populations of interest. Make this list available to CCO Intensive Care Managers who broker referrals from pediatricians to adult health care providers.

⁴ Association for Maternal and Child Health Programs [AMCHP]. (2014). *Standards for systems of care for children and youth with special health care needs. A product of the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project*. Retrieved from: https://www.lpfch.org/sites/default/files/field/publications/developing_structure_and_process_standards_charts.pdf. AMCHP & National Academy for State Health Policy [NASHP]. (2017). *Standards for systems of care for children and youth with special health care needs version 2.0*. Retrieved from: <http://www.amchp.org/programsandtopics/CYSHCN/Documents/Standards%20for%20Systems%20of%20Care%20for%20Children%20and%20Youth%20with%20Special%20Health%20Care%20Needs%20Version%202.0.pdf>.

8. Standardize language across all CCO handbooks. A primary complaint from parents to our Oregon Family-to-Family Health Information Center is that since CCO's are independent, each may "do things differently" from the next. A specific example includes use of the term "Exceptional Needs Care Coordinator" (ENCC) instead of "Intensive Care Manager." Families associate the term "intensive care" with hospital-based ICU care.
9. Require CCOs to make public the foci of their pediatric quality improvement (QI) projects and the results of their QI efforts.
10. Require CCO nurse call lines and care coordination services to be sourced in-state to increase the likelihood that they know about Oregon-specific resources. Care coordinators located outside of Oregon are ill-equipped to refer to appropriate community resources, and at a minimum, should have up to date and accurate resources.
11. Require CCOs to adhere to the Health Evidence Review Commission's non-prenatal genetic testing guidelines. Establishing an etiologic diagnosis is valuable in for CYSHN; it can not only guide management, provide recurrence risks for the individual, but also can lead to treatment, and improve access to diagnosis specific resources.⁵ Families tell us that, especially at the time of transition to adult care, they are not eligible for services without a diagnosis. Genetic test technologies has improved drastically; diagnoses can be achieved in a significant percentage of children with suspected genetic disorders⁶ and can save costs by shortening the diagnostic odyssey.⁷ Among CCOs, we have experienced disparate policies and decisions around coverage of genetic testing. Currently, CCOs follow this guideline inconsistently.
12. Require CCOs to use the Western States' Regional Genetics Network's Centralized Advisory Program to authorize genetics services. This HRSA-funded program helps payers choose the most appropriate genetics tests in a timely fashion. Use of these evidence-based recommendations would ensure that CYSHCN receive the right genetics tests at the right time.
<https://www.westernstatesgenetics.org/project-activities/capags/>
13. Require that CCOs adopt the Medicare coverage criteria for specialty enteral formula (B4149) to provide safe and effective treatment for CYSHCN meeting those criteria. This formula category is currently not covered.
14. Require that CCOs expand the coverage criteria for oral nutrition supplements to include formulas for the treatment of metabolic diseases, such as those identified by Newborn Screening.
15. Require CCOs to (a) have Intensive Care Managers screen for incontinence needs, and (b) have staff proactively educate providers on establishing medical necessity for Category I Incontinent Supplies reimbursement. Stakeholders consistently report a financial burden on families of children over the age of three who need diapers. For example, one parent of a medically complex adolescent told us she regularly "makes rounds" to Salvation Army and Goodwill stores seeking diapers for her child.

⁵ American College of Medical Genetics and Genomics Board of Directors. (2015). Clinical utility of genetic and genomic services: a position statement of the American College of Medical Genetics and Genomics. *Genetics in Medicine*, 17(6), 505-507.

⁶ Sawyer SL, et al. (2016). Utility of whole-exome sequencing for those near the end of the diagnostic odyssey: Time to address gaps in care. *Clinical Genetics*, 89(3), 275-284. doi: 10.1111/cge.1265.

⁷ Monroe GF, et al. (2016). Effectiveness of whole-exome sequencing and costs of the traditional diagnostic trajectory in children with intellectual disability. *Genetics in Medicine*, 18(9), 949-956. doi: 10.1038/gim.2015.200.

16. Require CCOs to maintain a list of vendors who accept the Oregon Health Plan (OHP) for disposable items. If such a list already exists, then make it easily accessible to families on CCO websites. OCCYSHN stakeholders share that CCOs often tell families that they will pay for an item, but that families must find vendors on their own. Families are not always well-equipped to find vendors and assess costs, resulting in wasted time for everyone involved.
17. Require CCOs to have their own support staff to assist members with billing issues, similar to the Exceptional Needs Care Coordinators/Intensive Care Manager model. This would reduce long wait times on the OHP customer service lines.
18. Require CCOs to publish their empaneling process and procedures, and accept qualified independent providers. This would increase health care access, especially for mental health services.
19. Ensure parity for hippotherapy services, making it a covered benefit for children experiencing trauma and other mental health diagnoses.
20. Require that CCOs provide and promote funding for parents of CYSHCN to attend one educational conference or training related to the care of their child (through Health Related Services).
21. Develop a process to support families when their CYSHCN transitions between CCOs. Stakeholders report that when families move from one CCO to another, they often “get lost in the shuffle.” It would help to have a standardized plan that includes contact names at the new and former CCO, and a process for transferring records.

We are profoundly grateful for the Oregon Health Policy Board and Oregon Health Authority’s extensive effort to get public input for the next round of CCO contracts. Thank you for considering our recommendations on behalf of Oregon’s CYSHCN and their families. Please let us know if we can provide any additional information.

Sincerely,

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