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Health Systems Division Rules Advisory Committee

Dear Health Systems Division and Committee Members:

The Oregon Center for Children and Youth with Special Health Needs, or OCCYSHN, is the state public health agency for children and youth with special health care needs. On behalf of our director, Ben Hoffman, MD, I thank you for the opportunity to provide input into the care coordination rules for CCO 2.0.

The Maternal Child Health Bureau defines children and youth with special health care needs as those *"who have or are at increased for 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] The most recent state estimates, from 2016, show that nearly 1 in 5 Oregon children under 18 years of age has a special health care need.[2]

As the population definition implies, these children need care, services, and supports from a range of providers that include education; behavioral, medical, oral, and public health; and social services. Need for care that crosses system boundaries necessitates that families of children with special health care needs *"navigate a complex maze of programs that may result in barriers to services, increasing the potential for unmet medical, educational, and social needs"* (p.667-668).[3]

Robust and effective care coordination strategies can help ameliorate barriers for families and improve the health and well-being of children and youth as they mature into adults. An upstream approach to population care that prioritizes health, and not just health care, will benefit all children and youth, not solely those with special health care needs.

Thank you for considering our recommendations, and for your efforts to improve the quality of health care for Oregon's children.

Sincerely,

Marilyn Berardinelli

Marilyn Berardinelli
Systems and Workforce Development Manager
Oregon Center for Children and Youth with Special Health Needs

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[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] 18.5% or 158,652 children. http://childhealthdata.org/browse/survey/results?q=4562&r=39

3 Wood, D., Winterbauer, N., Sloyer, P., Jobli, E., Hou, T., McCaskill, Q., & Livingood, W.C. (2009). A longitudinal study of a pediatric practice-based versus an agency-based model of care coordination for children and youth with special health care needs. Maternal and Child Health Journal, 13, 667-676.

Comments and Recommendations Pertaining to CCO 2.0 Rules Sections

- 410-141-3860 Integration and Care Coordination
- 410-141-3865 Care Coordination Requirements
- 410-141-3870 Intensive Care Coordination

General comments:

1) Collaboration across systems, including all aspects of health (medical/physical, oral, mental and behavioral, education, public health, and developmental disability services) in care coordination for children and youth with special health care needs is required for effective integration of care into the community.

2) Clarify the definitions of "care coordination" and "intensive care coordination (ICC)" and application of these terms.

3) Clarify whether MCEs are assuring care coordination or providing care coordination or both. In the absence of such clarity, the responsibility for that assurance may be deflected.

4) Children and youth with special health care needs depend upon a range of community-based services to meet their physical, social-emotional, intellectual and developmental needs. OCCYSHN recommends coordinating care with the breadth of care coordinators and case managers across systems, allowing for integration of care in the communities where children and youth live, go to school and play.

5) Define "transitions of care." If the definition is related to discharge planning only, then it is necessary to account for other types of transitions of care. It is important to address transition from pediatric to adult healthcare systems for youth and young adults with special health care needs, including for both primary care medical home and subspecialty care and services. OCCYSHN is available to provide more information, if needed.

6) OCCYSHN recommends inserting a definition for "member" that includes "family, parent or caregiver."

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410-141-3860 Integration and Care Coordination

(3) Existing draft language: MCEs shall coordinate physical health, behavioral health, intellectual and developmental disability and ancillary services between settings of care, including appropriate discharge planning for short-term and long-term hospital and institutional stays that reduce duplication of assessment and care planning activities.

- Ancillary services for pediatric populations may look very different from ancillary services for adults. For example, children are more likely to utilize speech therapy services than adults.
- OCCYSHN recommends inserting *"MCEs will coordinate with ancillary pediatric services required by children and youth."*

(6)(b) Existing draft language: Ensure that each member has an ongoing source of care appropriate to their needs and a person or entity formally designated as primarily responsible for coordinating the services access by the member. The member must be provided information on how to contact their designated person or entity.

- Increased specificity will reduce ambiguity and be clearer to members or their families trying to find and access care coordination services. Substitute "unit" or "department" for "entity".
- OCCYSHN requests that MCEs assign care coordinators to children and youth with special health care needs.
- OCCYSHN recommends that MCEs provide written documentation identifying the Intensive Care Coordinator/ENCC assigned to the member (or to the member's family, in the case of a child). OCCYSHN recommends that MCEs use plain language and multiple communication modes (including print and electronic) to inform the member (or their parent/guardian) about how to access an Intensive Care Coordinator/ENCC.

(8)(c) Existing draft Language: The MCE shall implement systems to assure and monitor transition in care so that members receive comprehensive transitional care and improve members' experience of care and outcomes, particularly for transition between hospitals and long-term care, and ensure providers and subcontractors receive information on the process for members accessing care coordination.

- OCCYSHN calls out youth and young adults who are transitioning from pediatric to adult health care settings. It is important that pediatric and adult settings coordinate, so that youth and young adults have continuous access to both primary and subspecialty care and services. OCCYSHN recommends that MCEs provide coordination, communication and integration between pediatric and adult care network providers. OCCYSHN recommends that MCEs ensure the youth or young adult is established with an adult provider. (Established means the youth or young adult has attended at least one appointment with the identified adult care provider of record.)

(19) Existing draft language: MCEs shall monitor the effectiveness of their integration and care coordination efforts. MCEs must implement at least one outcome measure tool for care coordination at the PCP-managed care coordination level and one at the ICC Care Coordination level. CCOs shall collaborate with the Authority to develop statewide standards for care coordination and ICC.

- OCCYSHN strongly supports adopting care coordination standards from the National Standards for Children and Youth with Special Health Needs. The standards are currently used by Oregon's Local Public Health Authorities to administer the public health home visiting care coordination program called CaCoon. Aligning standards across Oregon's systems would benefit all children and youth. https://nashp.org/toolkit-national-standards-for-children-and-youth-with-special-health-care-needs/
- OCCYSHN recommends establishing an advisory committee to develop an outcome measurement tool for health care coordination services. The committee should include representation from child health organizations.

(21) Existing draft language: The MCE must identify a plan to improve the overall process of care coordination access for its members. This plan shall also include discussion of gaps in care coordination services and populations that need additional support and plans for improving the care coordination system within their CCO. This plan is subject to approval by the MCE board and must be updated semi-annually with milestones and accomplishments.

- OCCYSHN recommends specifying how the MCE Board will be informed about best practices for care coordination specific to pediatrics. This is needed in order to approve MCE care coordination plans.
- OCCYSHN recommends differentiating between pediatric and adult care coordination. Gaps in care coordination will look different for pediatric populations.
- OCCYSHN recommends defining how progress toward MCE care coordination improvement will be developed, monitored, tracked, and made available to the public.

410-141-3865 Care Coordination Requirements

(2)(a) Existing draft language: MCEs must use a universal screening process that assesses members for critical risk factors that trigger the need for intensive care coordination for high-needs members.

- OCCYSHN recommends clarifying terms "screening" and "assessment" for consistency.
- OCCYSHN recommends using a standardized risk assessment tool across MCEs to conduct universal screening. OCCYSHN recommends using the accepted method for identifying children and youth with special health care needs, the "CSHCN Screener" developed by the Child and Adolescent Health Measurement Initiative (CAHMI; Bethell et al., 2002). The CAHPS survey employs the screener when collecting data to describe Children with Chronic Conditions. This set of items could be included in the universal screening.

(6) Existing draft language: Care plans shall reflect the member's preferences and goals, and if appropriate, family or caregiver preferences and goals. Care plans shall be trauma-informed, culturally responsive and linguistically appropriate and person-centered.

- Care plans developed in collaboration across sectors increase efficiencies and integration of care. OCCYSHN recommends adding an additional item: (6)(e) For children and youth with special health needs, care plans will be developed in collaboration with care coordinators, care managers or case managers of community-based services.
- OCCYSHN recommends defining "culturally responsive" and "family-centered."

(7) Existing draft language: A member may decline care coordination and ICC. The MCE shall explicitly notify members that participation is voluntary, and that treatment or services cannot be denied as a result of declining care coordination.

- OCCYSHN recommends that there be a clear process for opting back in if a member declines care coordination.

(8) Existing draft language: An MCE's care coordinators must perform their care coordination tasks in accordance with the following principles: (A) through (G)

- OCCYSHN recommends a process for ensuring adherence to the principles of care coordination through documentation and tracking.

(8)(B) Existing draft language: Set agreed–upon goals for the member with continued CCO network support for self-management goals.

- OCCYSHN recommends substituting this language: *"Work with the member (or with their parent or guardian) to establish self-management goals. Identify the support the CCO network can offer in pursuit of those goals."*
- OCCYSHN recommends inserting (8)(H): A care coordinator will ensure continuity of care coordination by making a "warm hand-off" to a successor.

(9) Existing draft language: An MCE must facilitate transition planning for members. In addition to the requirements of 410-141-3860, care coordinators must take the following steps to facilitate transitions and ensure applicable services continue after discharge.

- OCCYSHN recommends inserting (9)(g): When a youth with special health care needs turns 17, the care coordinator will work with the youth or the youth's family to identify appropriate adult primary and specialty care providers and services.

410-141-3870 Intensive Care Coordination

General comment: OCCYSHN recommends the following clarification in Sections (2), (3), and (4): Do prioritized populations qualify for ICC, or do members of the prioritized populations who meet criteria based on assessment and screening quality for ICC?

(2) Existing draft language: "Prioritized Populations" means […populations listed]

- OCCYSHN recommends that children and youth with medical complexity be added to the list of prioritized populations. We also recommend adding young adults with medical complexity who may be lost to care if attention is not given to the transition from pediatric to adult care.

(6) Existing draft language: ICC activities include

- OCCYSHN recommends inserting: (6)(f) When youth with special health care needs turn 17, the care coordinator will work with the youth or the youth's family to identify appropriate adult primary and specialty care providers and services.

(14) Existing draft language: MCEs shall have a process to provide members in ICC who have special health needs with direct access to a specialist, e.g. a standing referral or an approved number of visits, as appropriate for the member's condition and identified needs.

- OCCYSHN strongly supports this rule.