



October 12, 2017

Oregon Health Plan Quality Metrics Committee  
Wilsonville, Oregon

Dear 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 am here to encourage you to **include metrics for children and youth with special health care needs among your menu of measures and recommend several endorsed measures** that can be obtained from Oregon's collection of Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey data.

The Maternal and Child Health Bureau defines Children and Youth with Special Health Care Needs (CYSHCN) as 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."*<sup>1</sup> 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.<sup>2</sup>

As the population definition implies, these children need care, services, or 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 CYSHCN *"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).<sup>3</sup> In Oregon, more than three times as many CYSHCN report one or more unmet services needs in the past 12 months compared to non-CYSHCN.<sup>4</sup>

*"Equity and Social Determinants of Health"* is one of 6 stakeholder themes described in the September 2016 report, *"Oregon's Health Care Data: Mapping a Path Forward."* If your committee is approaching your work with an equity lens, then measures that describe the care quality for children and youth with special health care needs should be included in the Health Plan Quality Metrics measure set.

Further, children and youth with special health care needs is a subpopulation of children that both public and private insurers should attend to. In 2011-2012, more than half (55%) of CYSHCN were privately insured<sup>5</sup> and just under half (44%) were publicly insured.<sup>6</sup>

<sup>1</sup> 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.

<sup>2</sup> 18.5% or 158,652 children. <http://childhealthdata.org/browse/survey/results?q=4562&r=39>

<sup>3</sup> 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.

<sup>4</sup> <http://childhealthdata.org/browse/survey/results?q=2505&r=1&r2=39&g=461&a=4083>

<sup>5</sup> <http://childhealthdata.org/browse/survey/results?q=2200&r=1&r2=39&g=461&a=4047>

<sup>6</sup> <http://childhealthdata.org/browse/survey/results?q=2490&r=1&g=461&r2=39>

Institute on Development and  
Disability

Oregon Center for Children &  
Youth with Special Health  
Needs

t 503 494-8303  
t 877 307-7070  
f 503 494-2755  
e occyshn@ohsu.edu  
w www.occyshn.org

Mail code CDRC  
707 SW Gaines St  
Portland, OR 97239

The health conditions experienced by CYSHCN fall among many different types of diagnoses, which is in contrast to adults, whose chronic diseases tend to cluster in a smaller number of specific diagnoses (e.g., cancer, diabetes, heart disease/stroke).<sup>7</sup> Consequently, measures of adult chronic disease cannot simply be applied to this subpopulation of children.

To monitor this important subpopulation of children, we propose that the following metrics be added to your menu **specifically disaggregated by CYSHCN**. OHA already collects data necessary for these metrics via the CAHPS survey, which is an endorsed data source in the CCO incentive metric framework.

1. Coordination of Care, NQF Measure 0719: These items are already included in the data collection.
2. Access to specialized services, e.g., needed treatment or counseling, special equipment, and therapy are CAHPS measures,<sup>8</sup> and results from 2013 show disparities between children with and without chronic conditions.<sup>9</sup>
3. CAHPS Composite: Access to care<sup>10</sup>
4. CAHPS Composite: Satisfaction with care<sup>10</sup>

We also encourage the addition of NQF Measure 1340, Children with Special Health Care Needs Who Receive Services Needed for Transition to Adult Health Care. CYSHCN who transition to adult health care without specific transition services are more likely to have poor outcomes compared to their peers, including higher hospitalization rates.<sup>11</sup>

Children and youth with special health care needs grow into adults with special health care needs, and thus our state needs to know that its systems are working for them and their families.

We thank you for your consideration of our recommendations and your efforts to improve the quality of health care for Oregon's children.

Sincerely,

Alison J. Martin, Ph.D.  
OCCYSHN Assessment & Evaluation Coordinator

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<sup>7</sup> Bachman, S.S., Comeau, M., & Long, T.F. (2017). Statement of the problem: Health reform, value-based purchasing, alternative payment strategies, and children and youth with special health care needs. *Pediatrics*, 139(s2), S89-S98.

<sup>8</sup> <http://www.oregon.gov/oha/HPA/ANALYTICS/CAHPS%20documents/Banner%20Books%20101.pdf>

<sup>9</sup> Oregon administers the Children with Chronic Conditions CAHPS supplemental item set, which includes the nationally accepted set of items for identifying CYSHCN.

<sup>10</sup> <http://www.oregon.gov/oha/HPA/ANALYTICS/CCODData/2017%20Measures.pdf>

<sup>11</sup> White, P., McManus, M., McAllister, J., & Cooley, C. (2012). A primary care quality improvement approach to health care transition. *Pediatric Annals*, 41(5), e1-e7. <http://www.gottransition.org/resourceGet.cfm?id=142>  
"NQF Measure Information" Inclusion of this measure also aligns with Healthy People 2020 goals: <https://www.healthypeople.gov/node/3501/objectives#4153>