



April 6th, 2017

Senator Elizabeth Steiner Hayward
P.O. Box 2281,
Portland, OR 97208
Email: Sen.ElizabethSteinerHayward@state.or.us

Institute on Development and
Disability
Oregon Center for Children
and 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

Dear Senator Steiner Hayward and Health Care Committee Members:

We write to offer comment on proposed Oregon Senate Bill 934.

Our center serves as Oregon's Title V Maternal and Child Health Block Grant agency for children and youth with special health care needs (CYSHCN). The National Survey of Children's Health (NSCH) 2011-2012, which are the most recent generalizable data available, estimated that 19.4% of Oregon's children – nearly one in five -- between the ages of birth and 18 years had a special health care need.¹ When a child has special health care needs it means that they have one or more chronic physical, developmental, behavioral, or emotional conditions. It also means that they require health and related services of a type or amount beyond that required by children generally.

By definition, this subpopulation of Oregon children need comprehensive, coordinated care among their various health, education, and service providers. Our 2015 statewide needs assessment concluded that care coordination is an aspect of medical home that is not well implemented for CYSHCN.² One of the identified barriers is the lack of reimbursement for provider time spent coordinating care. In addition, CYSHCN accounted for 45.4% of the total health care costs for children.³ Thus, it would be logical to pilot alternative payment methods that support care coordination for CYSHCN.

We recognize that participation in national primary care medical home payment models, such as CPC+ conducted by the Centers for Medicare and Medicaid Innovation, presents beneficial opportunity for Oregon to explore alternative payment models. However, these payment models generally do not include CYSHCN in their pilot stages. Therefore,

Mail code CDRC
707 SW Gaines St
Portland, OR 97239

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¹ National Survey of Children's Health. (2011-2012). Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12-20-2014 from www.childhealthdata.org.

² Martin, A.J., Gallarde, S., & Hartzell, M.S. (2015). *Oregon's children and youth with special health care needs: Title V Maternal and Child Health Block Grant five-year needs assessment findings*. Retrieved on March 17, 2017, from http://www.ohsu.edu/xd/outreach/occyshn/publications/upload/OCCYSHN_NA_FinalReport_06-22-2015.pdf.

³ Excluding dental, institutional, and long-term care and educational costs. Newacheck, P.W., & Kim, S.E. (2005). A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatric and Adolescent Medicine*, 159, 10-17.

- We recommend that SB 934 Section 4, page 4, ORS 414.653 (3) lines 17-22, include language indicating use of alternative payment methodologies for CYSHCN in Patient Centered Primary Care Home's (PCPCH) that serve at least 20% children patients.

The U.S. Maternal and Child Health Bureau and national standards identify seven core components for how systems of care should be organized to effectively support CYSHCN and their families.⁴ Many fundamentals of the national standards are mentioned in SB 934; however, two elements of the legislation could be strengthened support CYSHCN and their families: (1) individual care plans, and (2) transitional care.

Individual care plans for CYSHCN are strengthened when coordinated with community service providers outside of the PCPCH. Such cooperation well aligns with OHA's PCPCH Standard 5.E.3, Referral and Specialty Care Coordination. Therefore,

- We recommend that SB 934 Section 1, page 1, ORS 414.625, (2) (c) line 13 include the following language, "Individual care plans, which demonstrate cooperation with community service providers outside the PCPCH..."
- We recommend that SB 934 Section 8, page 5, ORS 414.625, (2) (g) lines 39-41 replace the following language "link services and care providers across the continuum of care" with the following language, "**to promote care coordination across providers and systems serving members (children) to the greatest extent practicable and if financially viable.**"
- We recommend that SB 934 Section 8, page 7, (2) (j) lines 1-4 include the following language, "Each coordinated care organization prioritizes working with members who have high health care needs,....., **and in the case of children, their families,** in accessing and managing appropriate preventive....."

Transitional care could be augmented to include transitional care from pediatric to adult models of health care when applicable. Transition requires communication and coordination between the pediatric PCPCH, the adult PCPCH, and other providers serving the youth. Transition services are critical to CYSHCN successfully obtaining needed and responsive ongoing health care as adults, yet we know that Oregon medical providers do not consistently address transition issues with CYSHCN and that there are a shortage of adult health care providers who are prepared to care for transitioning CYSHCN. Increasing the number of CYSHCN who receive all needed services to transition from pediatric to adult health care is a national priority for Oregon's Title V Block Grant. Therefore,

- We recommend that SB 934, Section 1, page 2, ORS 414.625 (2) (d) line 15, Section 8, page 6, ORS 414.625 (2) (d) line 29 include the following language, "Members receive comprehensive transitional care, including appropriate follow-up, when entering and leaving an acute care facility or long term care setting, and when applicable, from transitioning from a pediatric to adult care setting."

Please let us know if we can provide additional information. We thank you for your time and consideration of our comments and for your service to our state.

⁴ Association of Maternal & Child Health Programs (2014). *Standards for Systems of Care for Children and Youth with Special Health Care Needs* [White paper]. Retrieved March 17, 2017, from Lucile Packard Foundation for Children's Health: http://www.lpfch.org/sites/default/files/field/publications/developing_structure_and_process_standards_charts.pdf.

Sincerely,

Alison J. Martin, PhD
Assessment & Evaluation Coordinator

Laura Rodriguez, MSW
Systems & Policy Analyst