



June 9, 2020

TO: 2020-2024 State Health Improvement Plan PartnerSHIP
Subcommittees

RE: Feedback on 2020-2024 SHIP Strategies

Dear PartnerSHIP Subcommittee Members:

I am a pediatrician at Oregon Health and Science University, and the director of the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN). We are Oregon's Maternal and Child Health Bureau Title V public health agency for children and youth with special health needs. We appreciate your thoughtful framework for improving the health of Oregonians. Thank you for the opportunity to offer feedback.

The Maternal and Child Health Bureau defines children and youth with special health care needs (CYSHCN) 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 2017-2018, show that nearly 1 in 5 Oregon children under 18 years of age have a special health care need.² Improvements in the system of care for CYSHCN will improve the health and well-being of CYSHCN and their families, and benefit all Oregonians. All input offered here is made with the needs of Oregon's CYSHCN population in mind.

Access to Equitable Preventative Care

All CYSHCN should receive family-centered, coordinated, ongoing comprehensive care within a medical home³. Primary care remains the foundation of a pediatric medical home. Access to a high quality comprehensive medical home helps every child thrive, and achieve optimal emotional, developmental and physical health. OCCYSHN fully supports the direction of these strategies.

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 Child and Adolescent Health Measurement Initiative. 2017-2018 National Survey of Children's Health (NSCH) data query. Retrieved 06/03/20 from <https://www.childhealthdata.org/browse/survey/results?q=6919&r=39>

³ Standards for Systems of Care for Children and Youth with Special Health Care Needs, Version 2.0. Association of Maternal and Child Health Programs, the National Academy for State Health Policy, and the Lucile Packard Foundation for Children's Health. (2017). Retrieved 06/04/20 from https://www.lpfch.org/sites/default/files/field/publications/standards_v2_0.pdf

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In particular, the strategies under Goal #3 align with [OCCYSHN's work](#) for CYSHCN and their families in Oregon: *Implement systemic and cross-collaborative changes to clinical and community-based health related service delivery to improve quality, equity, efficiency and effectiveness of services and intervention.*

We have feedback on the following strategies:

- **Support alternative healthcare delivery models in rural areas.** Many families of CYSHCN have to drive more than 30 minutes to seek specialty and behavioral health care, so we strongly support measures that will increase access to care in rural and other underserved areas.
- **Increase access to dental care that is offered in schools, such as dental sealants and fluoride varnish.** It is also important to connect children to medical and dental homes in their communities for longer-term management of oral health needs. Development of programs supporting advanced practice oral health providers can help address workforce issues.
- **Increase access to prenatal care for low-income and undocumented women and improve access to sexual and reproductive health services.** These strategies align with federal and state maternal and child health priorities broadly, and are important steps in achieving health equity for CYSHCN of color.
- **Expand use of telemedicine in rural areas.** We support this strategy to increase access to care in rural areas. The success of this strategy in achieving equity will depend upon mitigating disparities in access to necessary technology, and ensuring access to low-cost, high speed internet services.

Adversity, Trauma and Toxic Stress

Home visiting programs and parent/caregiver supports are crucial to strengthening the system of care for CYSHCN and their families. We support a strengths-based approach to enhancing family resilience, which aligns with other existing initiatives such as shared care planning and Wraparound.

The strategies under Goal #3 are good examples of actionable and measurable steps toward making the system of care more trauma-informed: *Mitigate trauma by promoting trauma informed systems and services that assure safety and equitable access to services, and avoid re-traumatization.*

We have feedback on the following strategies:

- **Ensure access to family friendly policies, such as affordable, high quality, culturally responsive childcare and paid family leave.**

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Quality childcare and paid family leave are crucial to improving the health and wellbeing of families, especially those with CYSHCN. To be equitable for children and youth with disabilities, we recommend adding *inclusive* childcare.

- **Expand evidence based and culturally responsive prenatal and early childhood home visiting programs.** We strongly support including evidence-based practices in this strategy, but we also recommend adding *evidence-informed* practices. Allowing flexibility for evidence-informed initiatives will allow greater opportunity for innovation.

Behavioral Health

The behavioral health safety net in Oregon is threadbare, especially for CYSHCN. Improving the mental and behavioral health system for children and families will positively impact communities in Oregon, and will have positive repercussions on education, child welfare and juvenile justice. The behavioral health system must emphasize quality, coordinated care across the lifespan, and provide comprehensive, accessible services to all children in need. We recommend that the proposed strategies for behavioral health include the needs of children, youth and families, specifically.

A major gap in our behavioral health system is the lack of services in rural areas of the state, and in schools. We recommend adding a strategy that focuses on developing the behavioral health and primary care workforce to meet the needs of people of all ages in their communities.

In addition to the recommendations above, we have feedback on the following strategies:

- **Expand programs that address loneliness and increase social connection in older adults.** We recommend expanding this strategy to include parents and caregivers, especially those who care for CYSHCN. For too many families of CYSHCN, one or more family members often bear responsibility for providing the intensive care required for medical issues and activities of daily living. This can preclude employment and social engagement, leading to isolation. The [Oregon Family to Family Health Information Center](#) is one program that aims to support families and caregivers of children with special health needs in navigating complex health care systems and accessing necessary supports.
- **Require Housing First principles be adopted in all housing programs.** Families of CYSHCN experience disproportionately high

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levels of housing instability compared with the general population.⁴

OCCYSHN supports this foundational strategy to address housing disparities, and provide stability for families caring for CYSHCN.

- **Increase resources for culturally responsive suicide prevention programs for communities most at risk.** We recommend that subpopulations of youth at higher risk for mental and behavioral health conditions be acknowledged specifically. These groups include BIPOC (Black, Indigenous, and People of Color) youth, LGBTQ youth, and youth with special health care needs.

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Economic Drivers of Health

OCCYSHN supports these strategies to address the economic and social determinants of health, especially for the many families and caregivers who experience increased financial strain associated with caring for CYSHCN.

We especially want to communicate support for the following strategies:

- **Increase access to high speed internet.** High speed internet and cell phone service access are key to achieving equity in health care access for all children, youth, and families, especially those in rural and underserved areas. This has been exposed as a significant issue by the Covid-19 pandemic, as both education and health care have become dependent upon these resources, magnifying existing disparities.
- **Engage priority populations to co-create investments, policies, projects and agency initiatives.** As the primary support system for CYSHCN, families and caregivers should be equal partners at the table in matters pertaining to the health and wellbeing of children. We also support engaging youth in all programs and initiatives intended to benefit them.
- **Increase supports that address food insecurity, like SNAP, WIC, and school based food programs.** SNAP, WIC, and school-based food programs are an effective strategy for addressing poverty and food insecurity for families of CYSHCN. We strongly endorse increasing these supports.

Institutional Bias

According to the American Academy of Pediatrics, “Racism is a social determinant of health that has a profound impact on the health status of

⁴ Rose-Jacobs, R., Cuba, S. E. de, Bovell-Ammon, A., Black, M. M., Coleman, S. M., Cutts, D., Chilton, M., Heeren, T., Casey, P., Ochoa, E., Frank, D. A., & Sandel, M. (2019). Housing Instability Among Families With Young Children With Special Health Care Needs. *Pediatrics*, 144(2), e20181704. <https://doi.org/10.1542/peds.2018-1704>



children, adolescents, emerging adults, and their families... Disparities in educational access and attainment, along with racism experienced in the educational setting, affect the trajectory of academic achievement for children and adolescents and ultimately impact health.”⁵ The negative health impacts of institutional bias are compounded for CYSHCN. OCCYSHN fully supports these strategies. We recommend specifically acknowledging institutional bias as it relates to children and youth in special education programs.

We have feedback on the following strategies:

- **Require state agencies to commit to racial equity through investment to BIPOC communities and agency performance metrics.** We recommend including CYSHCN and their families in this strategy.
- **End school related disparities for black youth through teacher training, monitoring of data and follow-up with teachers and schools.** We recommend expanding this strategy to include black youth with special health care needs, as they experience school-related disparities.

Finally, we know that in light of the Covid-19 pandemic and impending budget cuts, it will be challenging to implement change, and to address the inequity that has plagued our communities. Improving equity and health in our state will never be an easy task. However, we must establish a North Star, and commit to meaningful change as we strive to ensure a brighter future for all Oregonians.

Thank you for the opportunity to provide feedback on this plan.

Sincerely,

A handwritten signature in black ink, appearing to read "Benjamin Hoffman", written over a horizontal line.

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⁵ Trent, M., Dooley, D. G., Dougé, J., Health, S. on A., Pediatrics, C. on C., & Adolescence, C. O. (2019). The Impact of Racism on Child and Adolescent Health. *Pediatrics*, 144(2), e20191765. <https://doi.org/10.1542/peds.2019-1765>