Oregon's Children with Special Health Care Needs
Five Year Needs Assessment Findings – October 2, 2020

CHAPTER SIX

Stakeholder Feedback on Title V Priorities for Children and Youth with Special Health Care Needs

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Stakeholder Feedback on Title V Priorities for Children and Youth with Special Health Care Needs

Oregon Title V Needs Assessment Chapter 6: Children and Youth with Special Health Care Needs

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OCCYSHN solicited input on Oregon's 2021-2025 national, state, and emerging block grant priorities for CYSHCN from a group of 43 stakeholders. Family members of CYSHCN, culturally-specific service organization staff, and mid-level local public health authority (LPHA) managers from 32 Oregon counties composed the stakeholder group. Thirty of the stakeholders participated (70% of those invited).

Stakeholder Request

OCCYSHN proposed prioritizing medical home and transition to adult healthcare for 2021-2025, as we did from 2016-2020. We asked stakeholders a short set of questions to gauge the extent of their agreement with our proposal. We summarize our rationale for the proposal and the stakeholder responses below.

Medical Home Rationale and Input

The American Academy of Pediatrics described a medical home as a practice that ensures care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective (AAP, 2002). Oregon's Patient-Centered Primary Care Home (PCPCH) Program encourages clinical practices to achieve Oregon's medical home standards. OCCYSHN coordinates with partners to advocate for inclusion of pediatric standards that would benefit CYSHCN. Care coordination is foundational to medical home, and it is essential for CYSHCN and their families (AAP Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee, 2014). In addition, standards of systems of care that serve CYSHCN and their families assert that the team of family and professionals who provide care to CYSHCN ought to provide coordinated care (AMCHP & NASHP, 2017). Cross-systems care coordination addresses interrelated medical, dental, mental and behavioral, social, educational, and financial needs to achieve optimal health and wellness outcomes (MCHB, 2017).

OCCYSHN's 2015 Needs Assessment pointed to a unique opportunity to promote care coordination for CYSHCN through partnerships with LPHAs for the 2016-2020 block grant cycle (Martin, Gallarde, & Hartzell, 2015). OCCYSHN specifically focused medical home strategies on providing CYSHCN with family-centered, cross-systems care coordination; that is, coordinating care among families, health, education, and community service providers. Our strategies align with PCPCH Program Standards, elements of Oregon's Public Health Modernization, and Early Learning Hubs' direction to ensure that care is coordinated for young children.

National Survey of Children's Health (NSCH) 2016-2017 results suggest that Oregon CYSHCN still do not receive effective care coordination and referrals when needed (CAHMI, 2020). Additionally, families of Black and Latino CYSHCN described many challenges getting health care services for their CYSHCN. For example, Black families reported that they had difficulty accessing behavioral and mental health and

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specialty care services (Gallarde-Kim, Smith, Roy, et al., 2020). Some Black families reported that they had to persistently advocate to get services for their CYSCHN (Gallarde-Kim, Smith, Roy, et al., 2020). In some instances, health care providers did not accept their insurance, or the services they needed were not covered by their insurance (Gallarde-Kim, Smith, Roy, et al., 2020). Families of Black CYSHCN also reported encountering racial stigmatization (e.g., stereotyping, labeling, etc.) (Mendible, 2019) in the health care system, which exacerbated the difficulty of getting services for their child (Gallarde-Kim, Smith, Roy, et al., 2020). Families of Latino CYSHCN in Central Oregon described long wait times for appointments, and a lack of local providers and quality care (e.g., misdiagnosis, lack of attention to child's needs, lack of follow up after appointments) were impediments to getting the care their child needed (Gallarde-Kim, Bisso-Fetzer, Roy, et al., 2020). Like families of Black CYSHCN, families of Latino CYSHCN reported that they had to persistently advocate for their child to get services, and that they experienced racial stigmatization in health care settings (Gallarde-Kim, Bisso-Fetzer, Roy, et al., 2020).

Our cross-systems care coordination strategies seek to change the way that the partners in the system of care for CYSHCN communicate and engage with one another. Such changes require time. We have made great strides with our partners since we initiated these strategies in 2016-2017. We would like more time for organizations to test and implement change to improve care coordination for children and families. Therefore, we proposed keeping medical home as a Title V strategy for CYSHCN for the 2021-2025 block grant cycle.

We asked stakeholders to rate the extent to which they agreed with keeping medical home as a national priority using a zero to five rating scale based on the Fist to Five Voting and Consensus (NASCO, n.d.; see Exhibit 6.1). Nearly all respondents (93.3%) supported (three) or rated highly (four, five) OCCYSHN's proposal to keep medical home as a priority. Reasons for supporting the medical home priority, as well as concerns about keeping it, follow. Additionally, respondents provided considerations and recommendations to improve the medical home priority.

Exhibit 6.1. Respondents Ratings of Support to Keep Medical Home Priority in 2021-2025

Response Option	Count
5 = I love selecting medical home; I will champion its selection.	10
4 = I like selecting medical home; it is a good idea.	12
3 = I will support its selection.	6
2 = I have concerns but will go along with its selection.	1
1 = I have serious reservations, but choose to move forward with selecting it.	1
0 = This is a terrible idea that I cannot support.	0
Total	30

Rating of Four and Five

Twenty-two out of 30 stakeholders expressed strong support for keeping medical home as a priority (see Exhibit 6.1). The stakeholders reported that the medical home is essential to families receiving family-centered care, and sets the foundation for optimal health care for CYSCHN and their families. The stakeholders reported that care coordination, increased collaboration, and culturally responsive care are needed for families. These stakeholders also offered suggestions to improve the medical home. These included providing more linguistically responsive services; providing referrals and resources for families; and understanding and addressing families' barriers and challenges.

> *"Effective care coordination, assisting families with service referrals and connecting to a medical home is important work, and we hear similar needs in our community."*

> *"There is still a great need for improvement in this area: people connecting with a medical home in an authentic way, and providers being genuinely responsive the needs of the families and children they serve; including cultural responsiveness and access to services."*

Rating of Three

Six of the 30 stakeholders rated supporting the medical home priority a three (see Exhibit 6.1). Their suggestions for improving the medical home were often consistent with suggestions made by stakeholders who expressed strong support for maintaining medical home as a priority. For example, stakeholders reported the need for more cross-system care coordination, increased cultural awareness, and improved collaboration between health care providers and public health.

> *"I agree [with the medical home priority]; we need more time to develop cross-system care coordination."*

Rating of One and Two

Two of the 30 stakeholders supported maintaining medical home as a priority, but they expressed concerns about it as a priority (see Exhibit 6.1). Although respondents recognized that medical homes improve access to medical care, they pointed to the need for cultural and diversity training among health care providers. In addition, stakeholders reported that LPHAs need help from primary care providers to better facilitate shared plans of care. The stakeholders suggested that primary care provider support will allow LPHAs to focus on supporting the medical home.

> *"If we are referring to medical home I support that but, if we continue to focus on Shared Plans of Care, we at local health departments often cannot get the PCP to the table and really the PCP's office should be convening these."*

Transition to Adult Health Care Rationale and Input

Care coordination is a foundational element of medical home. Preparing for the transition from pediatric to adult health care is a component of high quality care coordination. NSCH 2016-2017 results suggest that Oregon children generally, and CYSHCN specifically, do not receive services necessary to transition to adult health care (CAHMI, 2020). Our participatory needs assessments with the Sickle Cell Anemia Foundation of Oregon and the Latino Community Association identified transition-related challenges. Both groups of families reported experiences in which the health care system failed to prepare them for transition. In some focus groups, families of Black CYSHCN reported difficulty staying involved in their youth's care after they turned 18, because of patient privacy laws (Gallarde-Kim, Smith, Roy, et al., 2020). Family members reported that they needed to stay involved, because their child was not ready to assume responsibility for their own health, and because the family did not trust that necessary care would be provided without their involvement (Gallarde-Kim, Smith, Roy, et al., 2020).

Families of Latino CYSHCN described a range of concerns that included losing insurance and paying for care once their child turned 18 to "having to start over from scratch" with a new set of health providers caring for their child (Gallarde-Kim, Bisso-Fetzer, Roy, et al., 2020). Because OCCYSHN's is the primary voice championing transition at a state level, and because some health systems are beginning to see the value of well-executed transition, we proposed keeping transition as a Title V strategy for CYSHCN for the 2021-2025 block grant cycle.

We asked stakeholders to rate the extent to which they agreed with keeping transition to adult health care as a national priority using the same rating scale as we used for the medical home priority. Nearly all respondents (90%) rated their support as a three or higher for our proposal (see Exhibit 6.2). Reasons for supporting the transition to adult health care priority, as well as concerns about keeping it, follow. Additionally, respondents provided considerations and recommendations to improve the transition to adult health care priority.

Exhibit 6.2. Respondents Ratings of Support to Keep Transition to Adult Health Care in 2021-2025

Response Option	Count
5 = I love selecting medical home; I will champion its selection.	9
4 = I like selecting medical home; it is a good idea.	9
3 = I will support its selection.	9
2 = I have concerns but will go along with its selection.	1
1 = I have serious reservations, but choose to move forward with selecting it.	2
0 = This is a terrible idea that I cannot support.	0
Total	30

Rating of Four and Five

Eighteen out of the 30 stakeholders rated highly the proposal to maintain transition to adult health care priority (see Exhibit 6.2). Respondents recognized that there is a general lack of education and training for families and health care providers when a youth needs transition services. This lack of information makes it challenging for youth to navigate the adult health care system, which creates uncertainty and fear for families. Respondents provided many suggestions for improving the transition to adulthood health care priority. For example, respondents recommended finding payment options for health care providers who conduct transition activities. Other respondents advocated for greater cultural sensitivity among health care providers. Finally, some suggested starting transition services early in life and providing better outreach to families.

> *"… Having a road map to help families and providers navigate through this [transition] period is critical towards helping CYSHCN youth ease into adulthood with the skills and supports they need to be successful as adults. Advanced planning on the part of providers (education, health care, employment, etc.), parents, and youth can help make a smoother and more successful transition."*

Rating of Three

Nine out of the 30 stakeholders rated their support for maintaining the transition to adult health care priority as a three (see Exhibit 6.2). Respondents indicated that transition services will help youth understand and develop responsibility for their own health. The stakeholders suggested that providing awareness of services; training and educating families; and improving cultural sensitivity among health care providers are needed to improve transition to adult health care. Additionally, respondents noted that providing these services early on will help alleviate family concerns and anxiety when their youth reaches the legal adult age.

> *"This proposal will reduce high levels of anxiety and fear from parents who do not know what to expect when client reaches legal age and status of client's medical services once in adult health care."*

Rating of One and Two

Three out of the 30 stakeholders expressed concerns or reservations about the transition to adult health care priority (see Exhibit 6.2). Respondents agreed that transition to adult health care needs to be addressed for CYSHCN. LPHA respondents, however, reported that the population of young adults with special health care needs who are transitioning is a small population to serve. LPHAs experience challenges serving this population. In some cases challenges result because they do not receive enough referrals for young adults with special health care needs, and therefore cannot meet OCCYSHN contract goals. In other cases LPHA staff are not well-equipped to provide transition services, with the result that it takes more time than they can afford.

> *"… Our staff are not adequately trained with this age group; their expertise and reason for working here is to support pregnancy and infancy/toddlers populations. We don't have the infrastructure to support this age population (charting templates and knowing partner service agencies) … We have learned this is a great need in our community, and would like to be a supportive voice for care coordination to be available for this age range..."*

State and Emerging Priorities

As part of Oregon's Title V statewide five-year needs assessment, the Oregon Health Authority Maternal and Child Health Section reviewed existing public health and hospital community health needs assessments (OHA, 2020). This review helped OHA identify seven emerging need areas for Oregon's Maternal, Child, and Adolescent Health populations (OHA, 2020). Considering those seven, plus Oregon's three 2016-2020 state priorities, we asked stakeholders to select one or two areas that would best address the needs of Oregon CYSHCN and their families. The stakeholders most frequently identified (1) Social determinants of health and equity; (2) Toxic stress, trauma, adverse childhood experiences, and resilience; (3) Culturally and linguistically appropriate services; and (4) Social connectedness (see Exhibit 6.3). Oregon Title V leadership selected state priorities using used this stakeholder input, results of the 2020 needs assessment, and knowledge of Title V program capacity. The three areas selected were: (1) Social determinants of health and equity; (2) Toxic stress, trauma, adverse childhood experiences, and resilience; and (3) Culturally and linguistically appropriate services.

Exhibit 6.3. Respondent Ratings of Ten State and Emerging Priority Areas in 2021-2025.

Response Option	Count
Social determinants of health and equity	14
Toxic stress, trauma, adverse childhood experiences, and resilience[a]	10
Culturally and linguistically appropriate services[a]	6
Social connectedness	6
Child care	4
Adolescent mental health	3
Maternal mental health	3
Food insecurity[a]	2
Drug use and misuse: Impact on pregnant women and children	2
Adult alcohol misuse	0
Total	50

[a]Current (2016-2020 Oregon Title V State Priority Area)

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