

Institute on Development & Disability

Oregon Center for Children and Youth with Special Health Needs

Oregon's Children and Youth with Special Health Care Needs:

Title V Maternal and Child Health Block Grant Five-Year Needs Assessment Findings

June 22, 2015

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Supported in part by *Enhancing the System of Services for Oregon's Children and Youth with Special Health Care Needs*
Oregon Health & Science University, Grant: HRSA-14-030



Acknowledgements

The authors thank the following individuals for their invaluable contributions to this work: Elena Andresen, Ph.D.; Kathleen Anger, Ph.D.; Lyn Ayer, Ph.D.; Tamara Bakewell; Josiah Barber; Shelley Barnes; Marilyn Berardinelli; Sandy Bumpus; Carol Criswell; Susan Cushman; Alison Donnelly; Gillian Freney; Juan Bautista Garate; Matt Gonzales; Julie Harris; Hilary Heller; Beth Kessler; Alena Lam; Helen Cotton Leiser; Natalie Linton; Tami Martin; Lolita McLean, Alabama Department of Rehabilitative Services; Maria Ness; Caroline Neunzert; Robert Nickel, M.D.; Tobi Rates; Charlotte Schley; Rachel Smith; Laura Wilson; Staci Wendt, Ph.D.; Jody Wright; and Christine Yim. In addition, OCCYSHN appreciates tremendously the families, community-based providers, medical practices, and other partners who helped promote and disseminate and who completed our needs assessment surveys.

The authors also thank OCCYSHN's Title V Block Grant partner: the Oregon Health Authority Maternal and Child Health Section, and in particular the following individuals: Kathryn Broderick; Nurit Fischler; Frederick W. King, Ph.D.; and Cate W. Wilcox.

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Introduction

In 2011-2012, the National Survey of Children's Health (NSCH) estimated that 19.4 percent (166,596) of Oregon children between the ages of birth to 17 years had a special health care need. Children and youth with special health care needs (CYSHCN) are "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" (McPherson et al., 1998). CYSHCN experience complex health problems, chronic illnesses, and disabilities. Due to medical complexities, CYSHCN also tend to have higher health care costs compared to non-CYSHCN. CYSHCN account for 45.4 percent of the total health care costs for children (excluding dental care, long term care, educational, and institutional care costs; Newacheck & Kim, 2005). CYSHCN make more than twice as many physician visits, have 1.5 times as many emergency department visits, have more than 3 times as many hospitalizations, and spend about 7 times as many days in hospitals as children without special health care needs (Newacheck & Kim, 2005). In addition, CYSHCN face more inadequacies in health care, education, family health, and maintaining a healthy lifestyle, when compared to children without special health care needs (U.S. Department of Health and Human Services, 2011).

Title V Block Grant Five-year Needs Assessment

The Title V of the Social Security Act funds a block grant to every state to improve the health and well-being of mothers, infants, and children, including CYSHCN (U.S. Department of Health and Human Services, 2015). In Oregon, the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) partners with the Oregon Health Authority (OHA) Maternal and Child Health (MCH) section to implement the state's Title V block grant by focusing on Oregon's CYSHCN population and their families. The Title V block grant requires that each state conduct a statewide needs assessment every 5 years to determine "the need for (1) preventive and primary care services for pregnant women, mothers, and infants up to age 1; (2) preventive and primary care services for children; and (3) services for children with special health care needs" (U.S. Department of Health and Human Services, 2015). In Oregon, OCCYSHN assesses the needs of CYSHCN and their families in partnership with OHA's statewide Title V five-year needs assessment. The needs assessment results inform the legislatively required five-year state plan for the block grant and OCCYSHN's strategic plan.

Two key questions guided OCCYSHN's needs assessment. The questions were: (1) What are current needs of Oregon children and youth with special health care needs (CYSHCN) and their families, and (2) What are the challenges and strengths of the system of care serving CYSHCN? Within these broad questions, OCCYSHN staff identified a set of topics on which to focus its data collection: Access to Needed Services and Family Supports, Medical Home, Care Coordination, and Transition to Adulthood. OCCYSHN's rationale for selecting the last 3 topics was to explore 2 performance areas on which Oregon has performed poorly and align with OHA's needs assessment.¹

Among the questions guiding OHA's needs assessment, the agency sought to learn how the needs of the maternal, child, and adolescent population were similar to or different from those identified in the 2009-2010 needs assessment (Broderick & Martin, 2015). Within the topic of Access to Needed Services and Family Supports, OCCYSHN gathered data that described CYSHCN and their families' experiences related to the current (2010-2015) state Title V block grant CYSHCN priority areas (i.e., access to specialized health and health-related services, access to mental health services, and family support). OHA also sought

¹ These performance areas are further discussed in the findings section.

to learn how the needs of Oregon’s maternal, child, and adolescent populations aligned with the Federal Maternal and Child Health Bureau’s (MCHB) new Title V block grant priority areas for CYSHCN: Medical Home and Transition to Adulthood (U.S. Department of Health and Human Services, 2015). Thus, OCCYSHN gathered data that described Oregon CYSHCN’s experiences related to both priority areas. In addition, OCCYSHN focused on care coordination as a data collection topic because of its importance to CYSHCN receiving comprehensive, integrated care in a functioning medical home (VanLandeghem et al., 2014b), and because of the changing landscape of care coordination.

The purpose of this report is to summarize OCCYSHN’s needs assessment findings. The report begins with a brief discussion of the methods used to answer the needs assessment questions. The findings section follows. This section is organized by the national priority areas, Access to Needed Services and Family Supports, and System Challenges and Strengths. The report closes with a summary and conclusions section.

Methods Summary

OCCYSHN used a mixed methods design to understand the needs of CYSHCN and their families. The design incorporated quantitative and qualitative data from several sources. A description of each follows; Appendix A provides more in-depth detail. In addition to involving stakeholders as participants in the data collection, OCCYSHN involved stakeholders in the development of data collection instruments and in the interpretation of survey results.

National Surveys. OCCYSHN used results from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). The National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention, collected these data. OCCYSHN also used data from the 2011-2012 National Survey of Child Health, which also was collected by NCHS.

Stakeholder Surveys. OCCYSHN administered electronic and paper surveys in English and Spanish to families of CYSHCN between the ages of birth and 26 years, and to young adults between the ages of 12 and 26 years with a special health care need. OCCYSHN also administered electronic surveys to community-based medical providers who treat CYSHCN, and to professionals who provide care coordination services to CYSHCN and their families. Because the population of each of these 4 stakeholder groups is not known, and therefore cannot be sampled from, OCCYSHN used a snowball sampling approach in which OCCYSHN’s contacts were asked to complete the surveys or, in the case of organizational partners, disseminate the surveys to the organization’s constituency. This resulted in a convenience sample. Results cannot be used to generalize to these 4 populations, but do provide useful information about the types of existing needs, and about similarities and variations between stakeholder perspectives on needs. Exhibit 1 summarizes descriptive information about the survey respondents by stakeholder group.

Group discussions with CaCoon Public Health Nurses and Nurse Supervisors. OCCYSHN hosted a series of 4 regional professional development meetings for county public health nurses and nurse supervisors who

implement the CaCoon home visiting program.² The meetings occurred in Bend, Pendleton, Roseburg, and Tigard between September 22 and October 3, 2014. OCCYSHN staff facilitated a two-hour discussion at each meeting using a standard set of questions. In addition, these county health department CaCoon staff participated in a Nominal Group Technique in which they voted to identify priority areas of focus for their counties.

Key Stakeholder Panel Discussion. OCCYSHN invited professionals representing a wide range of organizations and institutions that serve CYSHCN and representatives of families of CYSHCN to participate in a facilitated discussion on December 10, 2014. Participants represented the following organizations: APS Healthcare; Child’s Health Alliance; county department of human and developmental disability services; county public health, including maternal and child health director; Early Hearing Detection & Intervention (EHDI) program; Greater Oregon Behavioral Health, Inc.; Oregon Child Development Coalition; Oregon Health & Science University Child Development and Rehabilitation Center (genetics consultant, nutrition consultant, and occupational therapist); Oregon Pediatric Society; Oregon Pediatric Improvement Partnership; parent of a CYSHCN; and Providence Swindells Family Resource Center. The discussion focused on the needs of CYSHCN and the capacity of Oregon’s system of services to address those needs. Participants also recommended priority areas of focus for OCCYSHN for the next 5 years.

OHA Partner Survey Results. OHA administered an electronic survey to professionals working in the public health, social service, health care, and early learning/education sectors from July to August, 2014 (Oregon Health Authority, 2014). Respondents represented both government (57%) and non-government (42%) agencies and organizations. A majority of respondents (79%) represented organizations that provide direct service. OHA used a snowball sampling approach in which its contacts were asked to complete the survey and to disseminate the survey to its partners. This approach resulted in a convenience sample. Seven hundred eighteen individuals responded to the survey.

Exhibit 1. Description of OCCYSHN Survey Stakeholder Groups

| Family | Youth & Young Adults | Medical Providers ("Providers") | Care Coordination Professionals ("Care Coordinators") |
|--|---|--|---|
| 675 responses 554 included (83%) ^a | 116 responses 109 included (94%) ^b | 26 responses All included (100%) | 65 responses 54 included (83%) ^c |
| <ul style="list-style-type: none"> 87% were parents. On average, child is 10.7 years old. 46% reported a Bachelor’s degree or higher. 34% reported a gross household income greater than \$65,000. 70% reported using public insurance (alone | <ul style="list-style-type: none"> On average, young adult is 17 years old. 38% were female; 51% were male. 58% reported having a learning disability; 40% reported Attention Deficit Disorder; 40% reported a mental health condition. 71% White | <ul style="list-style-type: none"> 65% were pediatricians. 62% work in a private clinic or practice. On average, have been in practice for 18 years. On average, over 69% of the children and youth served on a monthly basis have a SHCN. | <ul style="list-style-type: none"> Most reported working in a private practice or clinic (30%) or local health department (29%). 47% work in a PCPCH. On average, have coordinated care for CYSHCN for 7 years. On average, 48% of the children and youth |

² The Oregon Care Coordination (CaCoon) Program is a public health nurse home visiting program for families of children between the ages of birth and 21 years that have a special health care need. In addition to typical home visiting services, these nurses also provide care coordination services for children and their families.

| Family | Youth & Young Adults | Medical Providers ("Providers") | Care Coordination Professionals ("Care Coordinators") |
|---|--|--|--|
| <p>or combined with other sources) to pay for their child's health care.</p> <ul style="list-style-type: none"> • 77% described their child as White (vs. other racial categories). • 13% described their child as Latino. • 74% reported living in metropolitan counties; 15% in rural counties • 47% lived in Clackamas, Marion, Multnomah, or Washington counties. | <ul style="list-style-type: none"> • 16% Latino | <ul style="list-style-type: none"> • Most reported working in Multnomah (12) and Marion counties (7). | <p>served on a monthly basis have special health care needs.</p> |

^aIncluded if: (a) Had a child between the ages of birth and 26 years; (b) met our CYSHCN screening criteria, which were modeled after the Child and Adolescent Health Measures Initiative (CAHMI) screeners, and (c) lived in Oregon (although surveys missing the county response were included in our analysis).

^bIncluded if: (a) Was between the ages of 12 and 26, (b) reported at least 1 health condition, and (c) completed more than 1 question.

^cIncluded if: (a) Reported serving CYSHCN, and (b) completed more than 3 questions.

Findings

This section presents the findings that resulted from analyses of data collected by OCCYSHN, and OHA to the extent that the data collection addressed the CYSHCN population. Because of the breadth of topics covered by the needs assessment, contextual information describing the significance of the topic is included in each section. The findings are organized into 3 major sections. The first section addresses the Title V block grant national priority areas of Transition to Adulthood and Medical Home, which includes findings related to Care Coordination. The second section presents results on CYSHCN and their families' Access to Needed Services and Supports. This section describes services and supports that are reportedly easy and difficult for families of CYSHCN to access, and reasons for difficulty in access. The section also describes findings related to the current (2010-2015) state priority areas for CYSHCN. The last section addresses strengths and challenges that were identified in the systems that serve CYSHCN and their families. Often, the reasons reported for families experiencing difficulty in accessing services related to system challenges.

National Priority Areas

In addition to seeking to align with OHA's needs assessment goals, OCCYSHN also focused on Transition to Adulthood and Medical Home in its needs assessment, because these were the national performance outcomes on which Oregon performed most poorly. Six national performance outcomes have historically been used to assess the functioning of systems serving CYSHCN (age 0 – 17 years) in each state. The outcomes were measured using data collected from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). Exhibit 2 presents a description of each national performance

outcome and results for Oregon and the U.S. Only about one-third of Oregon youth with special health care needs (YSHCN) received necessary transition services, and just over 40 percent of CYSHCN received care in a medical home. Oregon trailed national results on all indicators, with differences ranging from 1.9 to 7.5 percentage points. Oregon's performance on Transition to Adulthood and Medical Home was similar to the nation as a whole.

Exhibit 2. Oregon's Performance on National Performance Outcomes Compared to the U.S., 2009-2010.

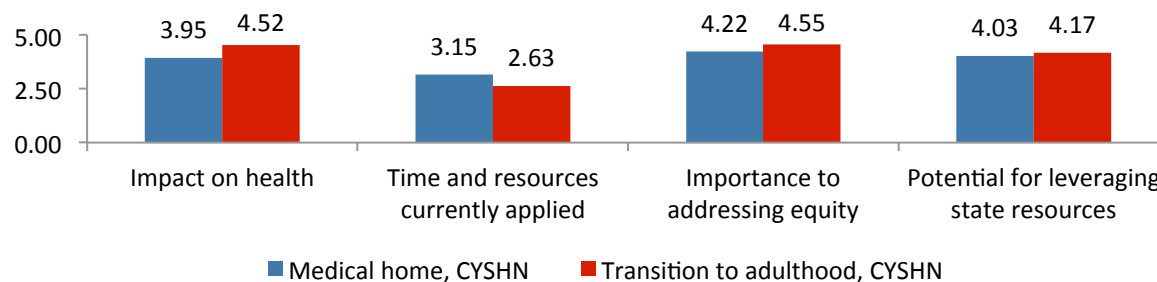
| Outcome | Oregon (%) | U.S. (%) |
|---|------------|----------|
| Transition to Adulthood. <i>YSHCN (12-17 years) receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.</i> | 35.6 | 40.0 |
| Medical Home. <i>CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home.</i> | 41.1 | 43.0 |
| Insurance and Financing. <i>Families of CYSHCN have adequate private and/or public insurance and financing to pay for the services they need.</i> | 55.8 | 60.6 |
| Easy to Use Services and Supports. <i>Services for CYSHCN and their families will be organized in ways that families can use them easily and include access to patient and family-centered care coordination.</i> | 63.4 | 65.1 |
| Family Professional Partnerships. <i>Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive.</i> | 69.8 | 70.3 |
| Early and Continuous Screening and Referral. <i>Children are screened early and continuously for special health care needs.</i> | 71.1 | 78.6 |

Source: U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2013). *The National Survey of Children with Special Health Care Needs Chartbook 2009-2010*. Rockville, MD: Author.

Note: Percentages are weighted.

OHA's partner survey asked respondents to rate 29 issue areas – the proposed Title V block grant national priority areas for all MCHB populations and the current (2010-2015) state Title V priority areas – in terms of (a) the issue's impact on the health of the respondent's community, (b) the time and resources currently applied to the issue, (c) the importance of the issue for addressing health equity, and (d) the potential for leveraging state resources to address the issue. Transition to Adulthood and Medical Home were included in the set of issues. Each issue was rated on a scale of 0 to 5, where 0 equated to not at all or none, and 5 equated to very great or very important. Exhibit 3 shows the average results for Medical Home and Transition to Adulthood. OCCYSHN interpreted these results to mean that these issues have a great impact on the health of the community, some resources currently are applied to both issues, the issues are important for addressing equity, and that there is potential for leveraging state resources to affect the issue. Medical Home was ranked: 18th in how much the issue impacts community health; 21st in importance to improve health equity; 4th in the amount of time and resources currently being applied to the issue; and 17th in the likelihood that application of more time and resources by public health agencies would make an impact on the issue. Transition to Adulthood was ranked: 3rd in how much the issue impacts community health; 8th in importance to improve health equity; 28th in the amount of time and resources currently being applied to the issue; and 10th in the likelihood that application of more time and resources by public health agencies would make an impact on the issue (Oregon Health Authority, 2014).

Exhibit 3. Mean Responses for Medical Home and Transition to Adulthood



Source: Oregon Health Authority 2014 Partner Survey

The next sections describe findings for Transition to Adulthood and Medical Home. The Federal Title V Block Grant requires that the Oregon Title V Program address at least 1 of 2 national priority areas for CYSHCN from 2016-2021: Medical Home or Transition to Adulthood. OCCYSHN asked its key stakeholder panel for their input on which priority area Oregon should select. The panel's recommendations also are included in this section.

Transition to Adulthood

The Maternal and Child Health Bureau describes Transition to Adulthood as “receiving the necessary services to transition to all aspects of adult life, including health care, work, and independence” (McManus et al., 2013; Oswald et al., 2013). In moving to an adult model of care, a CYSHCN could continue to work with their pediatric provider after turning 18 years old, or could transfer to an adult provider. The transition of youth to adulthood has become a priority issue nationwide, capturing the attention of the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians (U.S. Department of Health and Human Services [DHHS], 2015). Healthy People 2020 established a CYSHCN specific objective for transition: “Increase the proportion of youth with special health care needs (YSHCN) whose health care provider has discussed transition planning from pediatric to adult health care” (DHHS, 2014a).

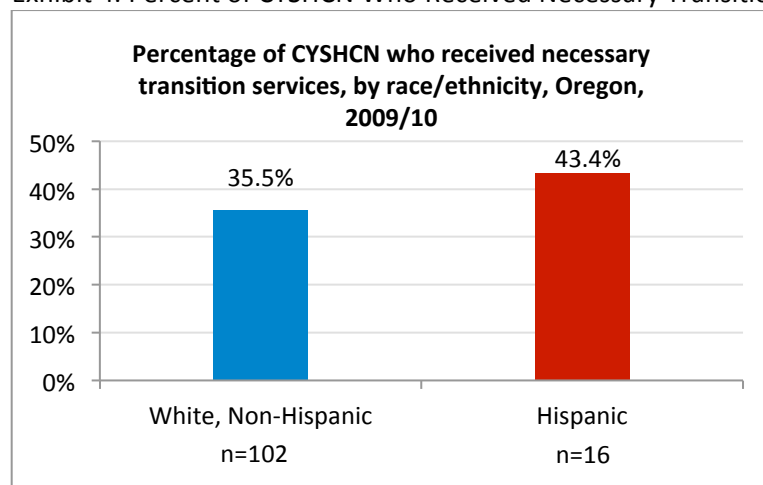
The National Consensus Framework also identified Transition to Adulthood as a standard for systems serving CYSHCN.³ This standard asserts that: “youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence” (VanLandeghem et al., 2014b). The National Consensus Framework has aligned with the standards outlined by Got Transition (www.gottransition.org). The standards assert that medical practices serving transition-age CYSHCN: (1) have a policy for preparing and planning for YSHCN and their families to move between pediatric and adult care systems, (2) track YSHCN who are ready to transition and monitor the completion of their transition process, (3) assess CYSHCN's readiness for transitioning to an adult provider and develop a plan of care that respects families' cultural beliefs, (4) work with CYSHCN and their families to develop a transition plan; (5) communicate transition plans to, and are available for consultation with, the new adult medical home, and (6) complete follow up 3 to 6 months after transfer to confirm its occurrence and elicit feedback (Got Transition, 2014b).

³ The National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs is an effort to develop a set of standards, across a diverse set of stakeholders that define a well-functioning health service system for CYSHCN (VanLandeghem et al., 2014a; VanLandeghem et al., 2014b).

Life course theory identifies transition from high school into adulthood as 1 of 2 critical transition stages that bear substantial influence on children's life course (Bethell et al., 2014). Most CYSHCN experience the same transition stages as children without special health care needs, although these stages may be reached at older ages depending on whether a child's condition naturally affects her or his developmental trajectory (Bethell et al., 2014). Over 90 percent of children and youth with special health care needs (CYSHCN) live to adulthood, but are less likely than their peers without special health care needs to complete high school, attend college, or be employed (DHHS, 2013, 2015). Health and health care have been identified as 2 of the key challenges to transitioning successfully (DHHS, 2015). Improved outcomes, such as reduced medical complications, better patient-reported outcomes, greater adherence to care, improved continuity of care, and lower costs, have been associated with transition planning (Got Transition, 2014a). In addition, research has shown that CYSHCN ages 12 to 17 who received transition services were half as likely to have a family who cut back or stopped working because of their child's health needs (Bethell et al., 2014).

The most recent population-level survey findings describing Transition to Adulthood needs are those from the NS-CSHCN, 2009-2010. The items included in this performance outcome were: (1) if a discussion about transition to adult care was needed, the discussion occurred, (2) if a discussion about changing health care needs as a child becomes an adult was needed, the discussion occurred, (3) if a discussion about transition insurance to maintain eligibility was needed, the discussion occurred, and (4) doctors usually or always encouraged responsibility for self-care (e.g., taking medication, understanding the youth's diagnosis, following medical advice; National Survey of Children with Special Health Care Needs, 2009/10). In Oregon, an estimated 36 percent of CYSHCN between the ages of 12 and 17 years received the services necessary to make appropriate transitions to adult health care, work, and independence (see Exhibit 2 above). The sample for racial and ethnic groups was too small to discern whether meaningful differences exist in receipt of transition services between CYSHCN of different races or ethnicities.

Exhibit 4. Percent of CYSHCN Who Received Necessary Transition Services by Race/Ethnicity, 2009/10



Data source: National Survey of Children with Special Health Care Needs

Note: The sample for other racial/ethnic groups was too small to meet standard for reliability or precision. The Child and Adolescent Health Measurement Initiative (CAHMI) advises using caution when interpreting categories that contain less than 50 cases. Percentages are weighted.

Based on their analysis of 2009/2010 National Survey of Children with Special Health Care Needs, researchers concluded that most CYSHCN do not receive the needed preparatory information to transition from pediatric to adult models of care (McManus et al., 2013). Analysis of data collected from OCCYSHN's surveys of Oregon young adults (12 to 26 years old) with special health care needs, families, and medical providers of CYSHCN yielded similar results. Less than one-third of respondents to OCCYSHN's family survey reported that their child's primary health care provider talked with them about how their child's care may change after the child turns 18. Of the 25 medical providers that reported that their practice serves YSHCN who are 14 years or older,

- 10 reported that their practice assesses readiness for transition to adult care. On average, providers reported beginning transition assessments between 15 and 20 years of age;
- 5 reported that their practice has a written policy addressing YSHCN transition; and
- 0 had a specified program to foster the development of desirable self-management skills or knowledge for transition.

About half of the youth respondents reported that their provider gives them “a lot of” or “some” help learning how to manage their own health and health care. Only 12 percent of surveyed youth reported that their health care provider talked with them about how their relationship with their health care provider will change when they turn 18. These findings mirror the conclusions of McManus and colleagues (2013) who stated that health care providers encourage CYSHCN to assume greater responsibility for their health care, but less frequently discuss moving to an adult model of care.

Key Stakeholder Panel Perceptions of Transition to Adulthood in Oregon

Panelists stated that there is momentum in the state around Transition to Adulthood in education and employment, but a lack of attention to transition in health care. Panelists explained that to continue to access health care in a medical home, a young adult with a special health care need(s) has to have financial resources (e.g., SSI), medical insurance (e.g., Medicaid), and other supports. The young adult should know how to access these supports, direct their care, manage their medications, make their appointments, and schedule annual check-ups. These are critical aspects of Transition to Adulthood – separate from transition issues associated with education and employment – and thus worth considering apart from medical home.

Panelists also discussed that there are 2 types of youth who will transition. The first is youth who have the capacity for some degree of self-management and independence; their independence might entail having some supports for the youth. The second type is youth who will never be capable of any self-management or independence. These youth and their families will need to address guardianship and other supports, and panelists expressed concern that the latter group currently is left out of transition discussions. Panelists added that even “med-peds,” or those physicians who have designed their practices to work with individuals across their lifespan, are unsure how to meet the needs of individuals who have more complex health conditions and will have reduced (or no) independence.

Panelists stated that current providers lack the expertise to provide transition direction to families. Panelists reported that providers, particularly those in family and internal medicine, lack knowledge of what CYSHCN need for transition and are unlikely to know what questions they need to ask to gain more knowledge. Similarly, panelists questioned to which providers CYSHCN would transition when they are

adults, because there are a lack of adult providers prepared to serve young adults and adults with special health care needs.

It may not be surprising, then, that panelists reported a lack of forethought about Transition to Adulthood from the medical home community. Lack of provider knowledge speaks to the education and training that is provided in medical school and during residency. In addition, providers need to stay abreast of current practices; however, panelists perceived that experts in Transition to Adulthood do not exist in Oregon, which limits the professional development or continuing education opportunities available for current providers. Panelists would like for pediatric providers to have automatic reminders that when children turn 12 years old it is time to begin conversations about transition. They noted that there is age-specific professional guidance (e.g., from the AAP) on the transition issues to discuss with youth.

Transition services...have been dismal. We have felt alone and confused all the way. Having deafness in addition to mild developmental disabilities...made it more difficult to find services. – Family Member of CYSHCN

There are almost no services available past high school in [my county] for young adults with autism. My young adult still needs social skills training as he often reads people incorrectly at work. He needs more support to find a full time job and a coach to support him to be successful. He also needs basic living skills like financial literacy. I'm retiring in a few years and I am concerned that he will not have insurance, a full time job or any way to live independently. - Family Member of CYSHCN

Medical Home

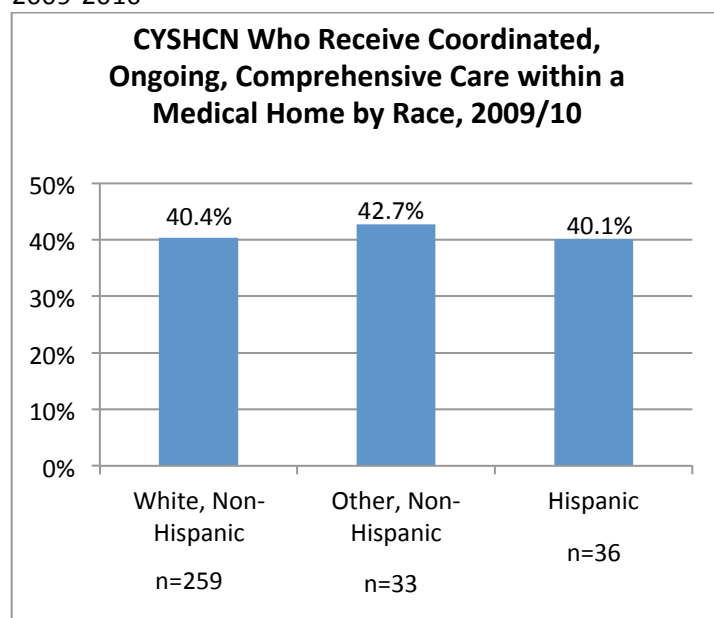
The Health Resources and Services Administration (HRSA) (n.d.) defines medical home as “a cultivated partnership between the patient, family, and primary provider in cooperation with specialists and support from the community.” In 1967 the American Academy of Pediatrics (AAP) introduced the medical home model as a standard of primary care provision for CYSHCN (National Center for Medical Home Implementation, n.d.). The AAP standard specifies that care provided in a medical home for children is: accessible, compassionate, comprehensive, continuous, coordinated, culturally effective, and family-centered (HRSA, n.d.).⁴ More recently, Healthy People 2020 established objectives to increase the proportion of CYSHCN who receive their care in family-centered, comprehensive, and coordinated systems (DHHS, 2014b). Research suggests that children with a stable and continuous source of health care are more likely to receive appropriate preventive care and immunizations; less likely to be hospitalized for preventable conditions; and more likely to be diagnosed early for chronic or disabling conditions. A lack of medical home has been associated with increased out-of-pocket health-related costs and fewer referrals to needed specialty care for families of CYSHCN (Boudreau et al., 2014).

⁴ The Maternal and Child Health Bureau Division of Services for Children with Special Health Needs (n.d.) defines family-centered care as assuring “the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services.” The NSCH measures this using items that focus on 6 experience of care questions: provider spends enough time with child, listens carefully to the parent, is sensitive to family’s values and customs, gives needed information; family feels like a partner; and gets a non-family member to interpret conversations with providers.

The National Consensus Framework, which proposes standards for systems serving CYSHCN and their families, includes Medical Home as 1 of its 10 domains of standards (VanLandeghem et al., 2014b). The Medical Home standards assert that a primary care provider and/or a pediatric specialist participate in an integrated care team. Integrated care teams provide care coordination; develop care plans; provide health care services 24 hours per day, 7 days per week; encourage the family to share in decision-making and provision of feedback on services; perform comprehensive health assessments; and conduct activities to support CYSHCN and their families in self-management of their child's health and care. (VanLandeghem et al., 2014b). Care coordination is particularly important; receipt of care coordination within a medical home has been shown to decrease the odds that a family of CYSHCN will have unmet specialty care needs (Warfield & Gulley, 2006).

Results of the 2009-2010 NS-CSHCN are the most recently available population-level data for Oregon CYSHCN that permit disaggregation by race. Those results showed that only 41 percent of Oregon CYSHCN received coordinated, ongoing, comprehensive, family-centered care within a medical home (see Exhibit 2). Available results suggest that there are not meaningful differences in the percentage of CYSHCN who are White, Non-Hispanic; Other Race, Non-Hispanic; or Hispanic that are seen in a medical home. These results are unable to generalize to CYSHCN who are Black, Non-Hispanic, which is a limitation of the data collection (see Exhibit 5). The NSCH also collects data on receipt of care in a medical home. Most recently results for this survey, 2011-2012, showed that 37 percent of CYSHCN did not receive family-centered care, one of the components of medical home.

Exhibit 5. Percent of Oregon CYSHCN Receiving Care Within a Medical Home by Race and Ethnicity, 2009-2010



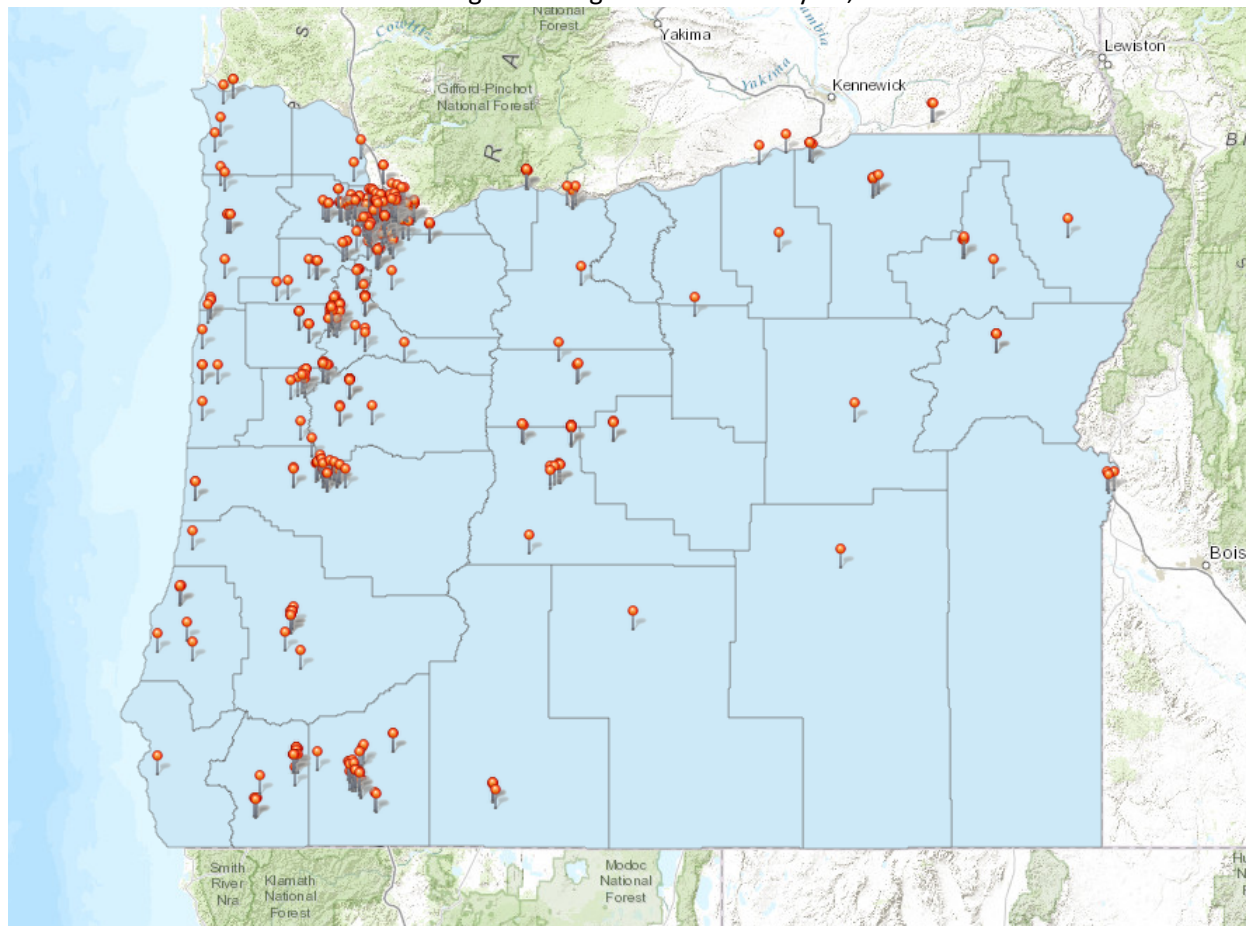
Data source: National Survey of Children with Special Health Care

Note: The sample for "Black, Non-Hispanic" was too small to meet standards for reliability or precision. The Child and Adolescent Health Measurement Initiative (CAHMI) advises using caution when interpreting categories that contain less than 50 cases. Percentages are weighted.

The Oregon Health Authority's Patient-Centered Primary Care Home (PCPCH) Program seeks to develop strategies to identify and measure what a primary care home does, promote PCPCH development, and encourage Oregonians to seek care through PCPCHs. None of its standards, however, explicitly require that practices address caring for CYSHCN. CYSHCN are *one example* of how a practice could meet Standard 5.C, Complex Care Coordination (Oregon Health Authority, 2013).

Patient-Centered Primary Care Homes (PCPCH) are not equally distributed around the state (see Exhibit 6). The majority of PCPCHs are clustered along the I-5 corridor between Portland and Eugene. PCPCHs are particularly sparse in central and eastern Oregon, and nearly non-existent in southeastern Oregon.

Exhibit 6. Distribution of PCPCHs throughout Oregon as of February 11, 2015



Source: Oregon Health Authority, Patient-Centered Primary Care Home Program website, 02-11-2015

Care Experience

Providing care for CYSHCN often requires flexibility on the part of health care providers. For example, CYSHCN often require a longer than typical appointment given the complexity of their health. The child might not be able to tolerate a typical waiting room setting. In its survey, OCCYSHN asked medical providers whether their practice provided a list of service options to families of CYSHCN. Overall, it appears that some service options are available in these practices. At least half of the responding providers reported that the following service options are available for families of CYSHCN:

- Longer appointments,
- Translation services,
- Same day appointments,
- Care coordination,
- Evening and weekend appointments,
- Prescription refill by email, and
- Reduced time in the waiting room.

A majority of both family and care coordinator respondents to OCCYSHN's surveys identified that it is at least sometimes difficult for parents of CYSHCN to obtain appointments as quickly as they are needed. More than half of the parents also reported being unable to schedule an appointment that was convenient to their work schedule and experiencing long waits in the waiting room before appointments. Few parents and coordinators reported that families experience challenges related to insurance or taking time away from work when in attempting to receive care from their child's primary health care provider.

Youth respondents to OCCYSHN's survey also were asked about their relationship with their primary health care provider. Of the 91 percent of youth who reported that they have a health care provider that they go to about their health condition, 78 percent reported that their health care provider "always" or "usually" listens carefully to what the young adult has to say. Fifty-eight percent reported that their health care provider "always" or "usually" explains things in a way that is easy for the young adult to understand.

Within medical homes, one aspect that as of yet may not be consistently or well implemented is the opportunity for family to provide feedback on services. Seventeen of the 26 medical providers responding to OCCYSHN's survey reported that their practice did not have a process, or that they did not know whether their practice had a process, for parents of CYSHCN to provide input and feedback on their practice's care of CYSHCN. Of the 9 providers whose practices did have a parent feedback process, 8 collected input through surveys. Four reported using a parent advisory group. Four also reported including parent participation on quality improvement teams.

Care Coordination

Care coordination is a component of medical home and centered on the needs of the patient and family. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes (see Exhibit 7; Antonelli et al., 2009). Effectively coordinating the multiple providers and services involved in a CYSHCN's care is crucial to meeting the many needs of CYSHCN and their families. The need for care coordination for CYSHCN is related to medical complexity, use of multiple providers and services, and family-based social stressors (Antonelli et al., 2008). Care coordinators serve as a member of the medical home team, assist in managing care transitions for CYSHCN across settings and developmental stages, and provide resources that match the patient or family's culture, health literacy level, and primary language (VanLandenghem et al., 2014). Effective care coordination has been seen to foster communication among health care providers, improve satisfaction, and decrease barriers to effective care (Wood et al., 2009).

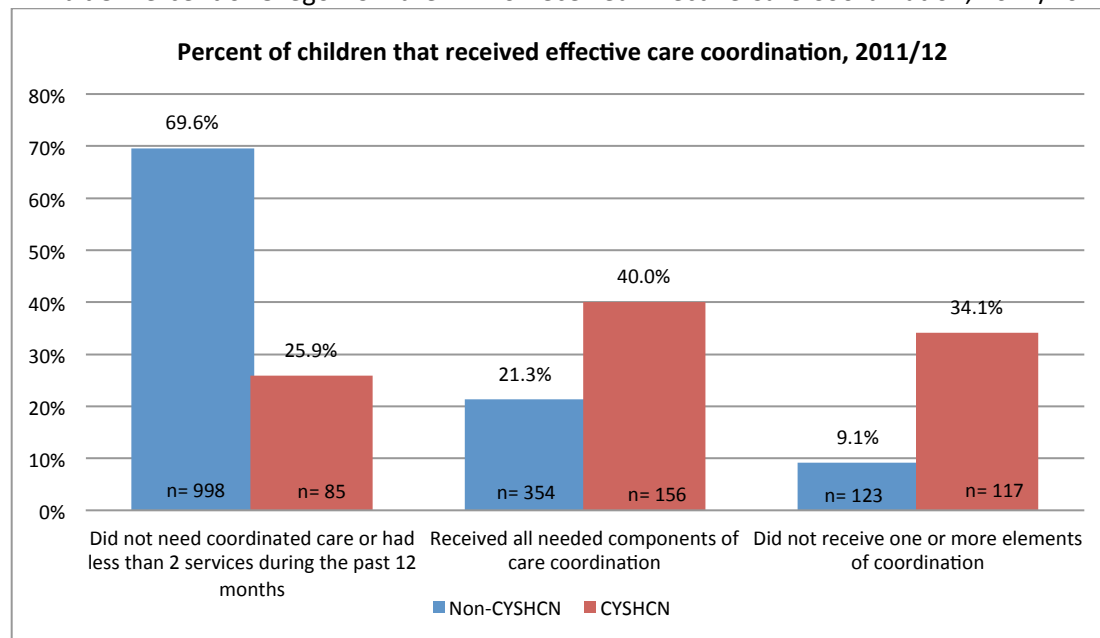
Exhibit 7. Functions of Care Coordination

The Functions of Care Coordination

1. Establish relationships with children, youth, and families through introductory visits dedicated to setting expectations for care coordination
2. Promote communication with families and among professional partners, and define minimal intervals between communications
3. Complete a child/youth and family assessment
4. Working with the family, develop a written care plan, including a medical summary, action plan, and, if needed, an emergency plan, that reflects mutual goals
5. Arrange for, set up, and coordinate referrals, and track referrals and test results
6. Provide condition- specific and related medical, financial, educational, and social supportive resource information, while coaching for the transfer of skills supportive of partnerships with families to care for their children and youth
7. Ensure the health care team integrates multiple sources of health care information; communicate this summary, thereby building caregiver skills and fostering relationships between the health care team and families
8. Support and facilitate all care transitions from practice to practice and from the pediatric to adult systems of care
9. Coordinate family- centered team meetings (across organizations as needed)
10. Use health information technology to effectively deliver and continually monitor care coordination and the effectiveness of service delivery

The results of the 2011-2012 NSCH are the most recently available that describe receipt of care coordination by Oregon families of CYSHCN at a population level. These results showed that 34 percent of Oregon CYSHCN did not receive 1 or more elements of care coordination, which is similar to national results (33%); however, only 9 percent of non-CYSHCN did not receive 1 or more elements of care coordination (see Exhibit 8). The survey's components of effective care coordination include communication between doctors when needed; communication between doctors and schools when needed; and getting needed help coordinating care.

Exhibit 8. Percent of Oregon Children Who Received Effective Care Coordination, 2011/2012.

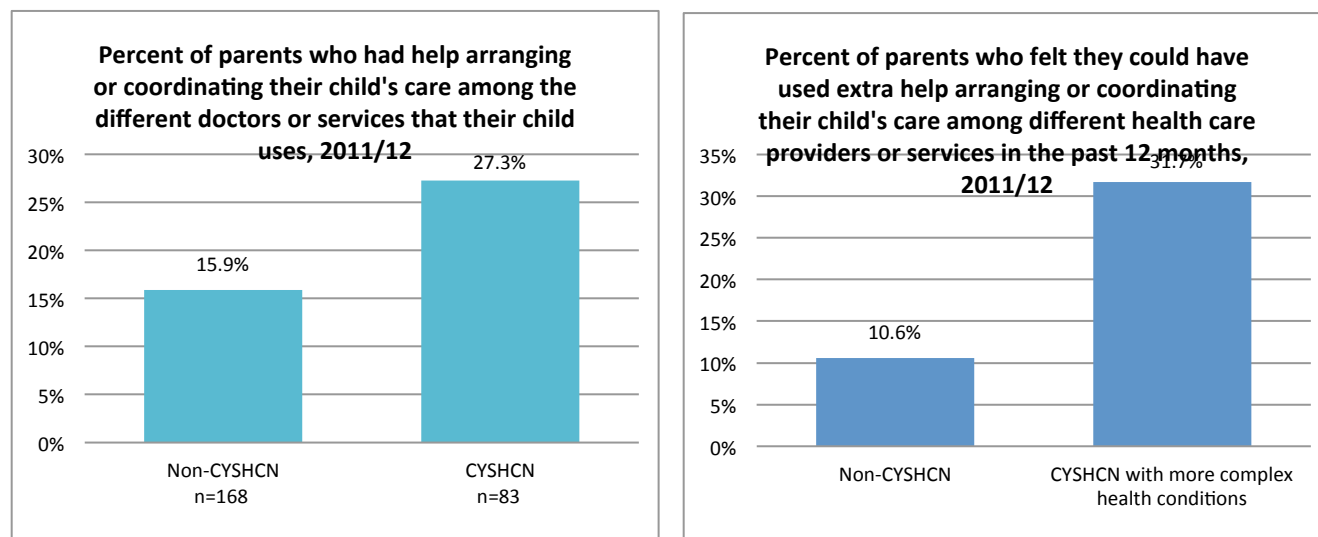


Data source: National Survey of Children's Health, 2011/12

Note: Percentages are weighted.

The 2011-2012 NSCH results also show that compared to non-CYSHCN, families of CYSHCN were more likely to have help arranging or coordinating their child's care among the different doctors or services that their child uses (see Exhibit 9). Parents of CYSHCN with more complex health conditions were more likely to report feeling that they could have used *extra help* arranging or coordinating their child's care among different health care providers or services in the past 12 months (see Exhibit 9).

Exhibit 9. Percent of Parents Who Had Help and Who Needed Extra Help Arranging or Coordinating Their Child's Care, 2011/12



Data source: National Survey of Children's Health 2011/12

Note: The sample for "CYSHCN with less complex health needs" too small to meet standard for reliability or precision. Percentages are weighted.

Forty-seven percent of families reported that they "rarely" or "never" receive as much help as they want arranging or coordinating their child's care. A nearly equal percentage of families (46%) reported "always" or "usually" receiving as much help as they want arranging or coordinating their child's care. More than one-third (37%) of respondents to OCCYSHN's family survey reported that someone helped them arrange or coordinate their child's care in the last 12 months. Those families most frequently reported that the following types of individuals helped them:

- Someone at the office of their child's primary health care provider (50%),
- Family member (30%),
- Mental health specialist (29%),
- Someone at their child's school (28%), and
- Occupational, physical, or speech therapist (27%).

"We (and I suspect many others) are in desperate need of someone to hold our hand in coordinating all the care our daughter needs and in finding providers with whom we can build long-term relationships."
— Family Member of CYSHCN

Care Coordination in Practice

During a typical month, care coordinators most often reported that they perform the following activities every day or most days:

- Track referrals for additional services (86%),
- Provide CYSHCN or their families with information on additional services or supports (e.g., educational, financial, medical, social) (61%),
- Locate services or supports in the community that could help CYSHCN or their families (54%),
- Set up referrals for additional services (52%), and
- Facilitate communication between health care providers, CYSHCN, and their families (45%).

Care coordinator respondents to OCCYSHN’s survey were given a list of various care providers and were asked, “In general, how often is it easy for you to coordinate with the following types of care providers to meet the needs of CYSHCN that you serve?” Results are presented in Exhibit 10 by level of ease in coordinating with each provider type. In general, a majority of respondents found it “always” or “usually” easy to coordinate with most types of providers. During the CaCoon regional discussions, staff often reported that these results were consistent with their experiences; specifically, the results for respite care providers resonated with CaCoon staff. The shortage of respite care providers in rural communities makes accessing a respite care provider difficult.

Exhibit 10. OCCYSHN Care Coordinators’ Perceived Ease Coordinating With Types of Providers

| Always/Usually Easy | Split | Rarely/Never Easy |
|--|---|--|
| <ul style="list-style-type: none"> • Allied health providers (e.g., occupational, physical, or speech therapists) • Primary care providers • Pediatric specialists • EI Services staff • Public health nurses • SPED school staff • School nurses • Behavioral & mental health care providers • Hospital discharge nurses | <ul style="list-style-type: none"> • Adult-oriented primary care providers (for coordination of transition care) • Day care providers • Dentists • Vocational or rehabilitation program staff | <ul style="list-style-type: none"> • Respite care providers |

Half of OCCYSHN family survey respondents reported that their child’s health care providers work “extremely well” or “moderately well” together to meet their child’s needs. Slightly more than half (54%) of families responded that their child’s primary health care provider needs to work with their child’s education or childcare provider (i.e., school, Early Intervention services, special education services, child care providers, or vocational/rehabilitation program). Those parents reported, on average, that these professionals work “moderately well” together.

During OCCYSHN's CaCoon regional group discussions, OCCYSHN asked CaCoon staff members what care coordination for CYSHCN looks like in their communities. The following characteristics emerged from all 4 of the regional discussions.

- Effective communication among key partners involved in their client's care is difficult.
- Care is fragmented; key partners tend to work in silos.
- CaCoon staff experience limited capacity to coordinate care effectively due to budget and staffing constraints.
- Some organizations do not utilize CaCoon, and families may not communicate fully with their CaCoon Nurse.

Miscommunication is a huge barrier to coordinating care. I don't have a problem calling them (doctors' offices, Head start), but communication is a barrier. Some of the other partners don't communicate back to me. – CaCoon Nurse

One barrier- is that all of us, the vast majority, are really short staffed. Medical Home, PHN, EI...yes, we could use more qualified trained staff to service more families. – CaCoon Nurse

We also asked CaCoon staff "what are, or what would be, the necessary ingredients for achieving comprehensive care coordination for CYSHCN in your community?" CaCoon staff's reports of what comprehensive care coordination *should* look like are characterized by the following.

- Connections exist throughout the community to help CYSHCN and their families obtain the services they need.
- Families' needs are at the center of care coordination efforts. Providers and professionals take a partnership approach to health care decision-making with the family/CYSHCN.
- Collaborative working relationships with partners involved in a CYSHCN/family's care, including shared goals, clear roles, trust, effective communication, transparency, and mutual respect focused on the needs and concerns of families.
- Shared electronic health record (EHR) is needed across the system serving CYSHCN. One CaCoon nurse reported that shared EHR can help with continuous communication among all partners so that those involved are attuned to the child and family's care.

Don't forget the family...It is always about the family needs. [We] don't want to involve all these agencies without including what the family needs. – CaCoon Nurse

We have a great group of professionals that we work with to ensure the success of my daughter. [Her doctor] is wonderful, understands my daughter and her needs (micro-preemie) and assists in coordinating (case manager from the clinic) with outside agencies (CaCoon, ESD-Early Intervention). Without all these key players in place, I'm not sure she would be doing as well as she has been. I am grateful for all they do. – Family Member of CYSHCN

OCCYSHN care coordinator survey respondents were asked to identify the 3 most important facilitators and 3 greatest challenges to providing care coordination for CYSHCN. The facilitators and barriers mirrored each other and CaCoon staff responses (see Exhibit 11).

Exhibit 11. Care Coordination Facilitators and Barriers According to Care Coordinator Survey Respondents

| Facilitators | Barriers |
|---|--|
| <ul style="list-style-type: none"> • The necessary resources to coordinate care (e.g., knowledge of local resources or contacts, time to coordinate, trainings). • The necessary services available to CYSHCN and their families. • Effective communication among key partners, including the ability to share medical records. • Collaborative working relationships. • Follow through from both key partners and families. | <ul style="list-style-type: none"> • A lack of communication, or miscommunication, among key partners (including families). • A lack of parent compliance and follow through. • A lack of interest by other health care providers. • A lack of local specialty services, particularly in rural communities. • There are challenges with insurance coverage (for example, limited visits allowed for specialty service visits) and challenges with navigating the insurance system. • A lack of capacity among coordinators and health care providers to carry out coordination activities. • Service providers have large client caseloads, which results in long waitlists for services. |

Respondents to OCCYSHN's medical provider survey most frequently reported that they *almost always* interact with the following providers when caring for CYSHCN: (a) occupational, physical, or speech therapists (89%), (b) counselors or therapists (69%), (c) psychologists (46%), and (d) Psychiatrists (39%). Medical providers were also asked to identify the 3 greatest barriers they face in attempting to coordinate care for CYSHCN. Their responses were similar to those from CaCoon staff and care coordinators. Providers most frequently identified as barriers: a lack of resources necessary for parents/guardians to manage their child's health needs; a lack of communication, or miscommunication, between providers, families, and other relevant parties; and challenges in sharing medical records or other information among providers, children, and families.

Medical providers and care coordinators both reported in OCCYSHN's surveys that the lack of effective communication is a huge barrier to coordinating care for CYSHCN. This is consistent with responses made during OCCYSHN's key stakeholder panel. Panelists shared that there is a need for better communication among providers, as well between providers and families. One panelist noted that the challenges with sharing medical records are a barrier to effective communication, stating *"it's very difficult to try to create a HIPAA form that allows communication of a group of people who work in different places."*

Shared Care Plans

Shared care plans are developed and shared among the primary care provider, family and child, and specialty providers. The care plan describes the family's needs, identifies their goals, addresses physical, oral, and mental health; describes the implementation and coordination of all services required by the family and child; and identifies the roles of the family and care team members including community organizations. Shared care plans have been identified as an integral aspect of care coordination for CYSHCN by national MCH leaders.

Shared care planning is a central component of coordination of care, an ideal quality within a pediatric medical home environment. Both for care within the medical home and in the context of health care reform, the effective use of care plans for patients living with chronic health conditions is an expectation... While any child may benefit from a basic care plan, children and youth with special health care needs should have a continuously evolving plan of care, which is updated and redesigned according to their developmental trajectory and each of life's transitions (McAllister, 2014, p. 2).

Key stakeholder panelists identified shared care plans as a component of care coordination because, “a good care plan involves the spectrum of services” needed for a CYSHCN. During the facilitated discussions with CaCoon public health nurses, they reported that the lack of a shared care plan impedes effective care coordination. In addition, CaCoon Nurses noted that providers should share care plans with all other providers involved in a CYSHCN's care.

In its surveys, OCCYSHN defined care plans as “a written document that contains information on a CYSHCN's health conditions, treatments, past medical history, and, for emergency room providers, signs and symptoms to watch for and how to respond.” Less than one-third (31%) of OCCYSHN family survey respondents reported that their child has a care plan. Of those, half reported that their child's care plan had been given to all of his or her health care providers. Parents most frequently reported that the following individuals helped develop the care plan: their child's primary health care provider (66%), themselves (57%), and other health care providers who work with their child (44%). Less than one-third (29%) of OCCYSHN youth survey respondents reported developing a written plan with their health care provider.

Almost half of care coordinators reported that during a typical month they develop a care plan with the family or youth every day or most days. Just over half of the OCCYSHN medical provider survey respondents (14) reported that their practice routinely completes care plans for CYSHCN. Twelve of these providers responded that they update care plans on an as needed basis. One provider said they update care plans annually; another said that care plans are updated when they have time. Panelists perceived that OCCYSHN's survey results showed a higher use of care plans than what their experience reflects.⁵ In their experience they have found that families do not expect their provider to supply or initiate a care plan, and *if* care plans are developed, the plans often are not used effectively or updated.

⁵ Pediatricians were the most frequent provider type that completed OCCYSHN's medical provider survey; panelists reported that this might explain why so many provider survey respondents reported that they use care plans.

Additionally, stakeholders expressed concern about the extent to which families participate in the development of care plans. Care plans need to meet families where they are; families might not understand their care plan if it is developed without their input. Moreover, if the care plan isn't culturally responsive, or if efforts were not made to communicate with families in their language, then it may appear that the family is not engaged, or that

I think a lot of times with families from other countries, we've decided what the care plan should be and we want agreement. But really, maybe they don't agree that any kind of intervention is necessary for their child with autism, because in their culture [families] just love [the child] and accept who [the child is].

-- Key Stakeholder Panelist

they are failing to follow through on care recommendations. Panelists also noted that when children's conditions span institutional silos (e.g., developmental disability and mental or physical health), care plans need to link families to services that will meet the range of needs associated with their child's condition.

Key Stakeholder Panel Perceptions of Medical Home in Oregon

Panelists stated that medical practices can be certified as a medical home, either through the state's PCPCH program or the National Committee for Quality Assurance (NCQA) Patient-Centered Medical Home Recognition program. Panelists noted, however, that to meet either of these certifications, practices do not have to demonstrate use of a care coordination approach for CYSHCN. Panelists identified care coordination as "critical" for CYSHCN, given the myriad providers with whom these children and families work; and they reported that care coordination is not occurring. Panelists stated that families cannot spend hours on the phone with all of the various providers that their child works with because families are busy dealing with their child's condition. Panelists also noted that health care providers are being pressured to see a greater number of patients and that insurance plans do not reimburse for care coordination services. Both of these pressures challenge providers' ability to coordinate care: *"We [have to] figure out a system of creating the time and support" for communication between providers.*

National Priority Area Recommendation

Panelists identified reasons for selecting either of the national priority areas. For example, in support of choosing Medical Home, some panelists stated that a "perfect" medical home is very holistic, and thus transition is *"a natural part of medical home."* The medical home would educate families about transition from conception. This would entail medical home staff "thinking ahead and planning." Panelists asked whether there are ways to think about medical home and transition and other services going together. For example, medical home could be thought of like wraparound services in behavioral/mental health; that is, the medical home would serve as the central entity maintaining all communication with the CYSHCN's other service providers, including education. In this way, the primary care provider could communicate with education to determine whether transition-related issues were included in the child's Individual Education Plan (IEP). In support of choosing Transition to Adulthood, other panelists agreed that transition should be incorporated into an ideal medical home, but noted that in reality CYSHCN often *"fall through the cracks."* Panelists noted that medical home issues like "empanelment" and "access" apply to all children, but those concepts apply differently to CYSHCN.

Ultimately, panelists identified both medical home and transition as important to clinical work with individuals and systems work for CYSHCN and their families.

Panelists observed, however, that selecting one seems to devalue the other and further noted that deciding between these two priorities seems to perpetuate the siloed manner in which the CYSHCN system of care has operated. *Panelists concluded that*

Given that what's measured tends to be what's focused on... we should measure both.

-- Key Stakeholder Panelist

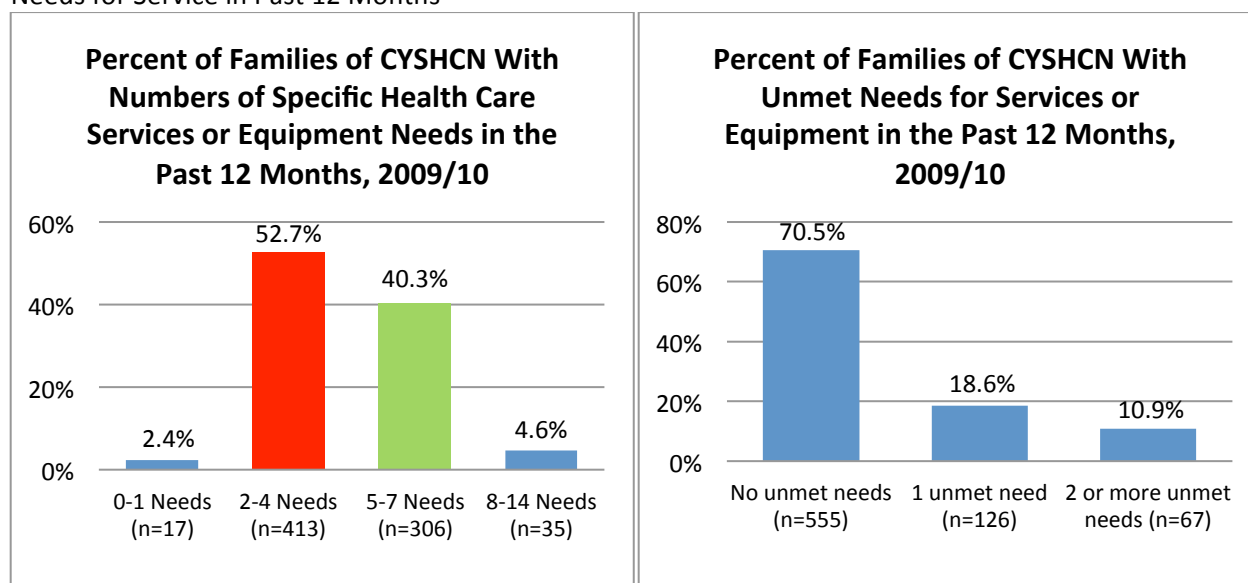
both issues should be selected. If Title V resources are available for only one, however, then transition should be selected because of other state efforts around medical home, which may not include transition for CYSHCN. Panelists also wondered how other efforts, like work with the Early Learning Hubs and the Health Policy Board could be leveraged to reduce the level of new resources needed.

Access to Needed Services and Supports

By definition, CYSHCN require a level of care, service, and support that is beyond the level typically needed by same-aged children. Consequently, CYSHCN often require care from numerous health and service providers. The National Consensus Framework also identified Access to Care as a domain of standards for systems serving CYSHCN. Standards in this domain assert that: the system has capacity to ensure geographical and timely contact with appropriate primary and specialty providers; pediatric specialists who have an established clinical relationship with a child as her or his clinical coordinator of care are able to serve as her or his primary care provider (PCP); families and youth have choice in selecting a PCP; the family has access to pediatric specialists specified in a child's care plan without prior PCP authorization; and transportation assistance is provided to families that experience challenges in accessing needed medical services (VanLandenghem et al., 2014).

Results of the NS-CSHCN, 2009-2010, are the most recent results available that describe the number of unmet service needs for a wide range of service types that can be disaggregated by state. These findings show that most families of CYSHCN have between 2 and 7 types of need for service (see Exhibit 11). Findings also estimate that 30 percent of Oregon families of CYSHCN have 1 or more unmet needs for service.

Exhibit 11. Percent of Families with Numbers of Health Care Services or Equipment Needs and Unmet Needs for Service in Past 12 Months



Data source: National Survey of Children with Special Health Care Needs

Notes: The survey asked about 14 types of health services or equipment (preventive medical, specialty care, preventive dental, other dental, prescription medications, physical/occupational/speech therapy, mental health, substance abuse treatment or counseling, home health care, eyeglasses/vision care, hearing aids/hearing care, mobility aids/devices, communication aids/devices, and durable medical equipment). The Child and Adolescent Health Measurement Initiative (CAHMI) advises using caution when interpreting categories that contain less than 50 cases. Percentages are weighted.

Results from the NSCH 2011-2012 showed that 17 percent of Oregon's CYSHCN received specialist services that were needed but experienced some problems getting those services. By comparison, only 4 percent of Oregon's non-CYSHCN families experienced some problems. Family respondents to OCCYSHN's survey were asked to identify three things that their child or family most needs but has a hard time obtaining. In response, 39 percent of parents reported specialty medical care for physical health (e.g., audiology care; chiropractic care; genetic testing; occupational, physical and speech therapy; prescriptions). Of those responses a significant number of parents specified needing allied therapies (e.g., occupational therapy, physical therapy, speech therapy) for their CYSHCN.

Access to specialized health and related services for CYSHCN was an Oregon Title V priority from 2010-2015. Results of our 2010 Title V needs assessment revealed that many specialized services for CYSHCN were located primarily in metropolitan areas, presenting families of CYSHCN living in rural areas with challenges in obtaining needed specialty services (Office of Family Health, 2010). The Oregon Health Authority's 2014 partner survey showed that out of 29 issue areas, this issue was ranked 12th in terms of impact on the health of the respondent's community, 14th in terms of its importance for addressing equity, 14th in the amount of time and resources currently being applied to the issue, and 12th in terms of the issue's potential for leveraging state resources.

OCCYSHN's survey asked parents to indicate the types of services their child needs, and then to rate how easy it was to obtain those services. Similarly, medical providers and care coordinators were asked to rate how well the families of CYSHCN they work with can access a list of services. Services that a majority of parents, care coordinators, and medical providers reported were easy to access are shown in Exhibit 12.

Exhibit 13 shows the services that a majority of survey respondents identified as difficult to access. Exhibit 14 shows the services that as many stakeholders reported were easy to access as those who reported were difficult to access. CaCoon staff in 2 regional meetings also shared that providers' perceptions may differ from that of coordinators and parents because once providers make a referral, they assume that the issue has been addressed and rarely track the referral to ensure the service was received.

Exhibit 12. Services Identified by a Majority of Stakeholders as Accessible to Families of CYSHCN

| Parents | Providers | Coordinators |
|---|---|--|
| <ul style="list-style-type: none"> • Prescription medications • Eye glasses or vision care • Teeth cleaning, fluoride treatments • Hearing aids or hearing care | <ul style="list-style-type: none"> • Preventive health care • Acute care services in a 24 hour clinical setting • Occupational, physical, or speech therapy • Pediatric specialty health care when needed • Receipt of coordinated care among health care professionals • Receipt of care when a diagnosis is lacking | <ul style="list-style-type: none"> • Preventive health care • Acute care services in a 24 hour clinical setting • Receipt of coordinated care among health care professionals |

Exhibit 13. Services Identified by a Majority of Stakeholders as Difficult to Access for Families of CYSHCN

| Parents | Providers | Coordinators |
|--|--|--|
| <ul style="list-style-type: none"> • Autism specific therapies • Respite care • Substance abuse treatment or counseling^a • Child care • Mobility aids • Behavioral/mental health services or counseling • Durable Medical Equipment • Home health care • Palliative care | <ul style="list-style-type: none"> • Respite care • Specialty dental care • Supports, e.g., income, peer, parenting resources, family, etc. | <ul style="list-style-type: none"> • Respite care • Acute care services for mental health • Specialty dental care • Support from families of CYSHCN with similar diagnoses |

^a Only 10 parents reported that their child needed this service.

Exhibit 14. Services That Equal Percentages of Stakeholders Identified as Accessible or Inaccessible

| Parents | Providers | Coordinators |
|--|--|---|
| <ul style="list-style-type: none"> • Genetic counseling • Nutrition counseling • Physical therapy • Speech therapy • Occupational therapy • Orthodontia or other dental care | <ul style="list-style-type: none"> • Families of CYSHCN with similar diagnosis^a • Receipt of needed services when families are undocumented^a • Allied health services (e.g., genetic counseling, nutritional counseling) • Routine dental care • Behavioral or mental health care when needed | <ul style="list-style-type: none"> • Receipt of care when families are undocumented^a • Supports, e.g., income, peer, parenting resources, family, etc. • Receipt of care when a diagnosis is lacking • Routine dental care • Non-acute behavioral or mental health care when needed |

^a The majority of medical providers reported that they did not know or had no opinion about how well the CYSHCN and families they work with were able to access this service.

During the facilitated discussions with CaCoon public health nurses, we asked them whether these results were consistent with their experiences in their communities. CaCoon staff often shared that results showing ease of access were not consistent with their experiences. In 1 site a nurse noted that the majority of the family respondents to the surveys (see Exhibit 1 above) differ from the families served by CaCoon, which might explain CaCoon nurses' differing perceptions.

CaCoon nurses also suggested that the ease with which CYSHCN can receive these services might be dependent on whether or not the family works with a care coordinator or the type of insurance covering the child. Using family survey responses to 15 health service questions, we compared the percentage of easy and difficult responses for those parents who reported that someone had helped them arrange or coordinate their child's care to the percentage of easy and difficult responses for those parents who reported that no one had helped them. Only 1 statistically significant difference resulted: parents who reported that it was easy to access prescriptions for their child tended to report that someone had not helped them arrange or coordinate their child's care; parents who reported that it was difficult to access prescriptions tended to report that someone did help. This questionnaire item inadequately captures the multiple dimensions that constitute quality care coordination. This finding should not be interpreted to indicate that care coordination is unhelpful; rather, it is more likely reflective of the complexity of the child and family's circumstances.⁶ Using the same data we also compared the percentage of easy and difficult responses for those parents who reported that their child's health care was paid for using a form of public insurance (i.e., Indian Health Services, Medicaid/Healthy Kids/OHP, or Medicare, n=203, 37%) or private insurance (i.e., private, work-sponsored private, Tricare, n=191, 35%). No statistically significant differences were found.

During the facilitated discussions with CaCoon nurses, they described the health-related service needs that families that they work with face. Exhibit 15 presents themes that arose in these discussions and examples of how these needs manifest in CaCoon nurses' communities. Participants in our qualitative data collections also described reasons why families of CYSHCN experience challenges accessing services for their child. Myriad factors were reported to contribute to families' inability to access services: living in rural Oregon, falling outside of the threshold to qualify for financial assistance, and a child lacking a diagnosis or a qualifying diagnosis. In addition,

- The type of insurance that a family has may influence their ease of accessing a service.
- Families may not be aware of available services. This may result from providers not communicating well to families what services are available, or families not understanding services due to language barriers, or the lack of an up-to-date central repository identifying available services.
- Some practices drop families who miss appointments. Practices use this approach because they have waiting lists; if a family misses multiple appointments, providers want to ensure that the appointments are available to other families. However, some families miss appointments for reasons beyond their control.
- Their child has a condition that crosses service systems (e.g., developmental disabilities and mental health) but is not clearly aligned with either system.

⁶ Appendix A elaborates on the tests of statistical significance.

- Their insurance company approves a limited number of visits (e.g., 3) for a service or therapy (e.g., speech therapy). The family and referring providers must then expend resources pursuing approval for additional visits.

The Systems of Services for CYSHCN section elaborates on several of these barriers.

Exhibit 15. Family Service Access Challenges According to CaCoon Nurse Experiences

| Health-Related Service Type |
|--|
| <p>Audiology and Hearing</p> <ul style="list-style-type: none"> • Families with children with hearing impairments have to work through Early Intervention (EI) to obtain services, which creates more hurdles. • Hearing aids are difficult to get depending on the child's age and where they are in the system. • The pediatric provider passed away and another provider has not been found. • Early Intervention (EI) no longer provides hearing aids. When they did, hearing aids were easy to obtain. • One audiologist is available for an entire southwestern county and has a 6-9 month waiting list. |
| <p>Dental care – Preventive</p> <ul style="list-style-type: none"> • Many dental providers do not accept OHP because reimbursement is not, or is perceived as not, adequate. • Long waiting lists (e.g., 3-4 months) exist. Families have difficulty accessing appointments at our FQHC without my assistance. Long waits exist because more families now have dental care access but there are not enough providers who accept OHP. • Providers that work well with CYSHCN are hard to find. CYSHCN are challenging to work with. • A larger provider in one region often cancels patients' appointments, has a long wait between appointments, and only fills one cavity per appointment, which results in cavities worsening. |
| <p>Dental care – Specialty</p> <ul style="list-style-type: none"> • Severely autistic children need specialty dental providers. • Anesthesia is hard to find for CYSHCN. • If a family needs dental procedures, they have to drive 2.5 to 3 hours to receive services. • OHP doesn't cover orthodontia. |
| <p>Durable Medical Equipment (DME)</p> <ul style="list-style-type: none"> • Insurance limits the frequency and type of equipment • DME is priced gouged for CYSHCN. |
| <p>Genetic Services</p> <ul style="list-style-type: none"> • Families with private insurance have difficulty accessing genetic counseling. • OHP does not cover genetics services. |
| <p>Medical Home</p> <ul style="list-style-type: none"> • Medical Home, public health nurse home visiting programs, and Early Intervention are all short-staffed. • Primary care providers need to better engage in ensuring that their patients' mental health needs are met through referrals. • The concept of medical home is not fully implemented as intended; we have a lot of work to do in this area. • Families' choices of providers are limited in smaller communities. This can be a benefit when the family likes the provider ("Their PCP is their OB. That's a great model") and difficult when the family does not. |

Health-Related Service Type

- A shortage of providers exists in one southern county.

Mental and Behavioral Health

- A shortage of providers exists, particularly in southern Oregon.
- A shortage of acute care services exists for children who are suicidal or have behavioral issues; hospital nurses are not comfortable caring for these CYSHCN.
- A long wait exists for families to have their child screened for Autism. Once a child is diagnosed, limited supports are available for the families.
- Some services are available to families with OHP that are not available to families with private insurance.

Nutrition Services

- Nutritional counseling is important but its availability is limited.
- There are no nutrition specialists in our area; smaller counties do not have them.
- We Skype with our Registered Dietician. It is not the best method.

Prescriptions

- Families have high prescription copays.
- Prescriptions are denied because authorizations are lacking.

Pediatric and Pediatric Specialist Care

- A shortage exists in rural areas.
- Some care practices will not see patients who live outside of their service area, which further limits family accessibility.
- Some pediatric specialists do not accept OHP.
- Services also are needed for families not covered by OHP.

Therapies (Occupational, Physical, Speech)

- Rural areas lack access to all of these therapists.
- Obtaining these services differs by insurance type.
- Local providers think that they have the skill sets to meet these needs.

Vision

- Providers lack awareness of local services (e.g., a monthly vision clinic).
- A shortage of vision providers exists.

I am a single mother with two children and a domestic violence survivor. My son needs occupational therapy, and it's very hard for me to pay for it because it's expensive. My hope is that someday or somehow I will be able to find the support and treatment that he needs. I will [try] my best for my kids, especially for my oldest with special needs... – Family Member of CYSHCN

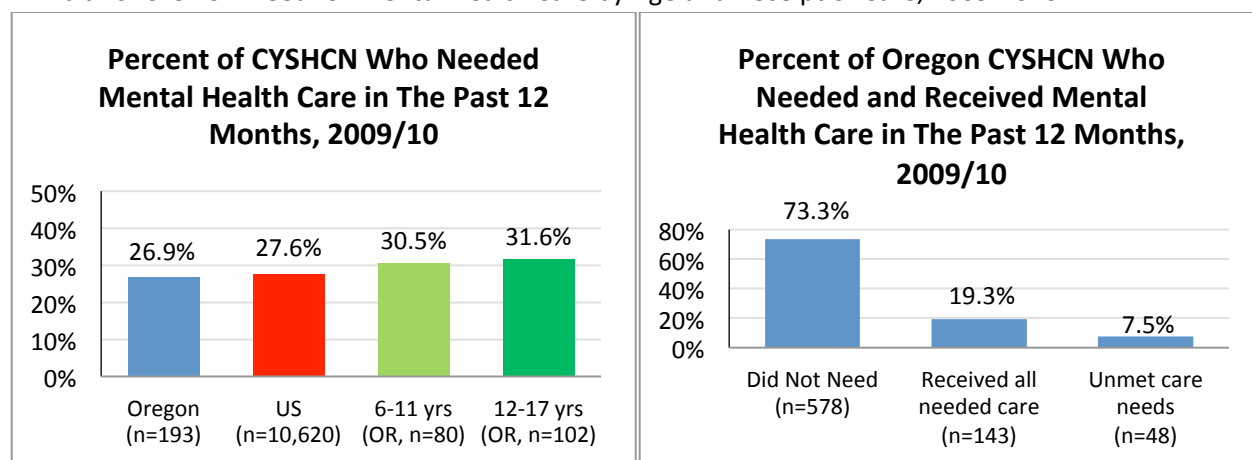
Mental Health

Access to mental health services was selected as an Oregon Title V state priority area for 2010-2015 based on the previous Title V needs assessment findings. Nationally, the most commonly reported service that was needed for CYSHCN but not received was mental health care or counseling (U.S. Department of Health and Human Services, 2013). A 2009 study found that 38% of families of CYSHCN enrolled in Medicaid had a child with a mental health problem in need of treatment. These parents most frequently

rated asthma, attention, and behavioral health problems as their child's top health problems (Agency for Healthcare Research and Quality, 2009). The National Consensus Framework for systems serving CYSHCN specifies access to mental health services in its Access to Care standards.

The most recent population-level survey results describing mental health care needs for CYSHCN come from the NS-CSHCN, 2009-2010. The Data Resource Center for Child & Adolescent Health provides these results disaggregated by age and state. These findings show that slightly more than one-quarter of Oregon's CYSHCN ages 2 to 17 years needed mental health care in the 12 months prior to the survey (see Exhibit 16). These estimates were slightly higher, however, for children 6 to 11 years (31%) and 12 to 17 years (32%). Of the children who needed mental health care, 7.5 percent did not receive all the care that they needed.

Exhibit 16. CYSHCN Need for Mental Health Care by Age and Receipt of Care, 2009-2010



Data source: National Survey of Children with Special Health Care Needs

Note: The sample for CYSHCN ages 0 to 5 years was too small to meet standards for reliability or precision. The Child and Adolescent Health Measurement Initiative (CAHMI) advises using caution when interpreting categories that contain less than 50 cases. Percentages are weighted

The majority of parents who responded to OCCYSHN's survey reported that autism-specific therapies and mental and behavioral health care were difficult to access (see Exhibit 13 above). A majority of care coordinators who responded to our survey report that it is challenging to access *acute* mental health services (see Exhibit 13.) As many care coordinators identified accessing *non-acute* mental or behavioral health services as challenging as those who identified them as accessible (see Exhibit 14.) Similarly, medical providers responding to our survey were split; as many identified accessing behavioral or mental health services as difficult as those who identified their access as easy.

Twenty-four percent of family survey respondents reported that mental or behavioral health services (e.g., Applied Behavior Analysis, autism counseling or services; behavior support; specialized counseling for children who are deaf and developmentally disabled, therapists, psychiatrists, and medical doctors that are reliable and understand Autism Spectrum Disorder) were 1 of 3 things that their child or family most needs but has a hard time obtaining. Non-acute Behavioral/Mental Health Care and Counseling was the second most popular priority area when CaCoon staff voted on priority issues to address within their community. During the facilitated discussions, CaCoon nurses described shortages of mental and behavioral health providers, long wait times for children to be screened for Autism, and service variation depending on the type of insurance a family has.

OCCYSHN’s key stakeholder panel discussed mental health as an important issue affecting CYSHCN and their families. They also reported that Oregon has a shortage of providers for CYSHCN, and that insurance often will not reimburse for mental health services. Panelists identified as important the integration of medical and mental health services. They also identified several systemic barriers to integration, such as financial barriers, HIPAA constraints on information-sharing, and shortages in the services that are available for a given diagnosis. Panelists reported that medical and mental health are more segregated for those served by commercial insurance compared to public insurance, which makes it especially challenging to ensure that CYSHCN covered by private insurance receive appropriate services. The systemic issues are elaborated on in the subsequent System of Services for CYSHCN Findings section.

My dream is to find a way for my autistic child to cope with anxiety. All paths I have taken have not worked. I have spent thousands on his therapies, speech & occupational therapy, when he was younger, but can't find help for mental health for him. – Family Member of CYSHCN

Transportation

On average, family survey respondents reported that the furthest distance they have to travel for their child to get care from any of her/his providers is 91 miles. Distances ranged from 0 to 5,626 miles (traveling across country.) More than one-quarter (27%) of the respondents reported having to travel the distance 12 or more times per year. Almost two-thirds (60%) of the respondents reported having to travel the distance 4 or more times per year. Twenty percent of family survey respondents reported that paying for transportation to get their child to any of her/his providers is “always” or “usually” hard.

CaCoon public health nurses consistently identified transportation, as an issue of access to needed health and health related services, as a priority needing to be addressed within their communities. Across all 4 CaCoon regional meetings, transportation received the most votes as the priority area to address within their communities. Further, transportation received the most or second most votes in all 4 meetings. Between the CaCoon meetings and the key stakeholder panel, participants described transportation issues associated with more populous and more rural areas of the state. For example, key stakeholders stated that when available, public bus transportation is challenging for families to navigate when traveling with their child with special health needs and other siblings or multiple children with special health needs, particularly when rides are long and require transfers.

CaCoon nurses, particularly in rural areas, discussed the dearth of services available in their counties. The lack of providers results in families needing to travel, often considerable distances, to obtain the care that their child needs. Such travel creates challenges for families. For example, in a 2-parent household, only 1 parent will be able to travel with the CYSHCN because the other parent cannot take time off from work. If there are siblings, the parents then must locate child care for the siblings or take the siblings to the provider appointment. One nurse recalled that a parent had to leave her CYSHCN alone at Doernbecher Children’s Hospital during treatment to return home to care for other children. When travel is involved, CaCoon nurses said that parents often will try to coordinate multiple specialty appointments in one day. If something comes up which necessitates the parent canceling the appointment, the parent then must spend meaningful time cancelling all of the appointments (one CaCoon nurse said it took her 1.5 hours to cancel all such appointments for a client).

The dearth of services also results in overuse of Emergency Departments, even though it can be a challenge for families in rural areas to travel to those services. One nurse said, *“The ER is way overused...in these isolated communities. If [the reason for the visit is] for preventive health care, I bet they would just go home [rather than get the care].”* CaCoon nurses also talked about challenges that can result from jurisdictional boundaries. For example, some families of CYSHCN live closer to Boise, and thus it would be easier for families to travel there to receive care; however, OHP will not reimburse for those services. Another nurse noted, however, that in southern Oregon, OHP was reimbursing some services from California providers.

CaCoon nurses reported that families they work with cannot afford gas to travel to and from, for example, OHSU. Additional costs arise if the family needs to stay overnight because of the distance (e.g., southern Oregon to Portland). CaCoon nurses talked about the frustration of a family finally obtaining an appointment with a specialty provider, and then not being able to afford the travel. According to key stakeholders, although OHP provides transportation services to families insured by OHP, their use is difficult for these families because

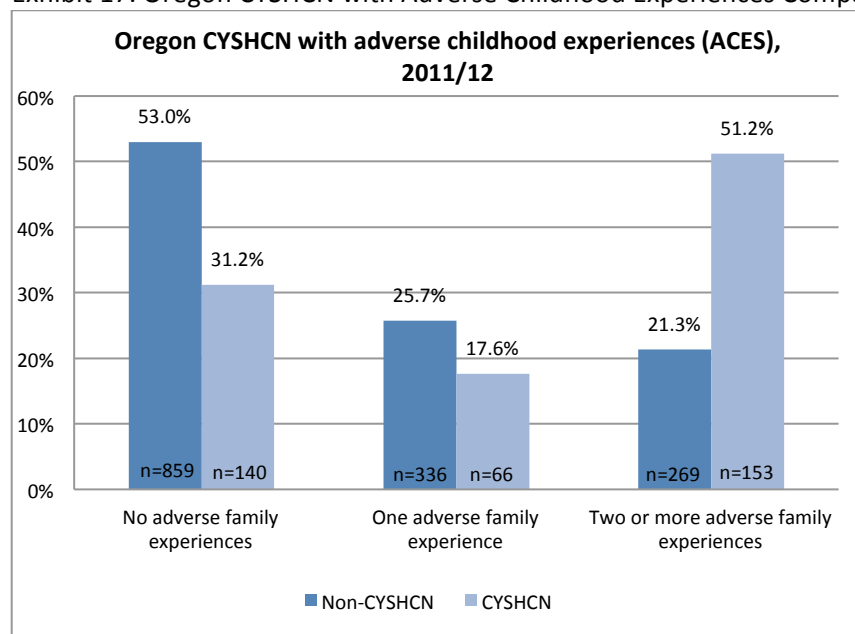
- Making a request can take over an hour by phone and requires a significant amount of information that not all families can manage.
- Only 1 parent and the child with the appointment can travel; siblings and other parents cannot. CaCoon staff understood that this was due to insurance liability if there was an accident.
- Parents must request language translation service, if they need this service, which requires that they know how to request the service.
- Parents can wait at home for an hour to be picked up, which then results in their child missing their appointment. Missing an appointment can result in a child being dropped from a provider’s service.
- Parents can wait for hours at the clinic to return home because taxis would prefer a typical fare.

Eastern Oregon desperately needs reasonably accessible, equitable access to specialists and highly trained therapists. A nearly 600 mile round trip visit to the doctor is expensive; fuel cost, time off of work, food and lodging all add up quickly. It also causes my child to miss valuable instruction time at school and disrupts his routine which causes a lot of behavior issues. – Family Member

Family Support

Families of CYSHCN reported experiencing more stress than families of non-CYSHCN. According to the 2011-2012 NSCH, 25 percent of parents of CYSHCN reported feeling stress from parenting during the past month compared to 7 percent of parents of non-CYSHCN. Results also showed that almost half (49%) of the parents of CYSHCN, compared to less than one-fifth (16%) of the parents of non-CYSHCN reported “sometimes” or “usually/always” feeling that their child is much harder to care for than most children of their child’s age. Financial challenges related to their child’s medical condition also may contribute to parents’ stress. About 21 percent of families of Oregon CYSHCN had problems paying or were unable to pay for their child’s medical bills. Average out of pocket health expenses for families of CYSHCN are twice those for other families. CYSHCN are also more likely to experience 2 or more adverse family experiences than non-CYSHCN (see Exhibit 17).

Exhibit 17. Oregon CYSHCN with Adverse Childhood Experiences Compared to Non-CYSHCN, 2011/12

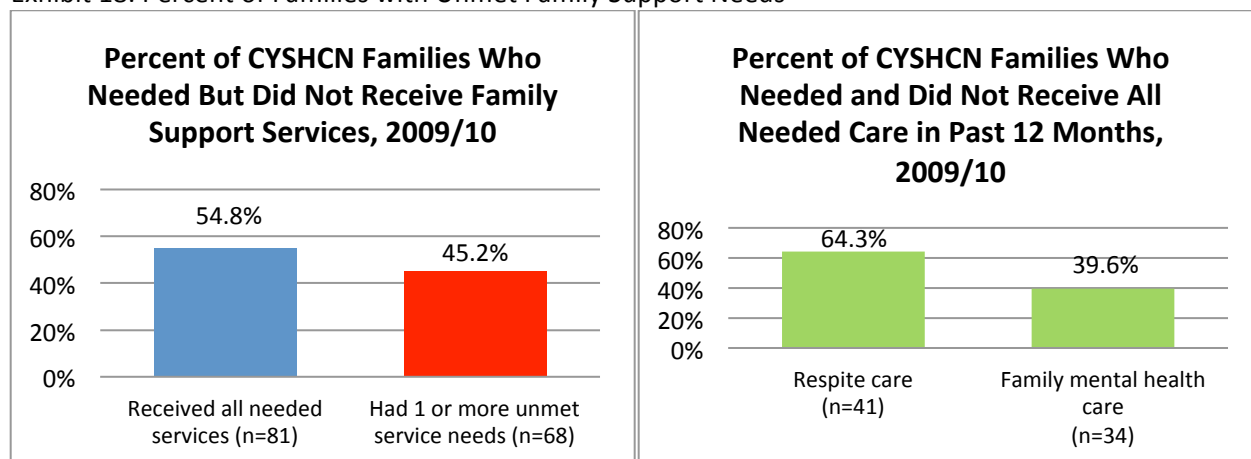


Data source: National Survey of Children's Health

Note: The survey asked about 9 types of adverse childhood experiences (socioeconomic hardship, divorce/separation of parent, death of parent, parent served time in jail, witness to domestic violence, victim of neighborhood violence, lived with someone who was mentally ill or suicidal, lived with someone with an alcohol/drug program, and treated or judged unfairly due to race/ethnicity). Percentages are weighted.

The National Consensus Framework includes access to Community-Based Services and Supports as 1 of its 10 domains of standards (VanLandenghem et al., 2014). The standards assert that that CYSHCN and their families are provided access to comprehensive home and community-based supports, provided by their health plan and/or in partnership with other community agencies including family organizations, public health, education, Early Intervention, Special Education, child welfare, mental health, and home health care organizations. The standard specifically draws attention to the accessibility of respite, palliative, and hospice care (VanLandenghem et al., 2014). The Maternal and Child Health Bureau suggested that examples of services that could help families of CYSHCN are (1) family counseling/mental health care, (2) genetic counseling (for advice on inherited conditions related to the child), and (3) respite care (another caregiver watches the child to provide a break for parents or other family members; US Department of Health and Human Services, 2013). The 2009-2010 NS-CSHCN collected data from parents on whether their family needs, and if so, has access to, these three service types. Nearly one-quarter of respondents (22%) reported that their family needed respite care, genetic counseling, or mental health care. Of those, 45 percent had 1 or more unmet service needs (see Exhibit 18). Sixty-four percent had unmet needs for respite care; nearly 40 percent had unmet needs for family mental health care. More recently, results of the Child Family Survey (part of the National Core Indicators Project) indicated that 74 percent of Oregon families of children with developmental disabilities do not have access to needed respite services (Human Services Research Institute (HSRI) and National Association of State Directors of Developmental Disabilities Services, 2014).

Exhibit 18. Percent of Families with Unmet Family Support Needs



Data source: National Survey of Children with Special Health Care Needs

Note: The survey asked about 3 family support services: respite care, mental health counseling, and genetic counseling. Genetic counseling was not included in the second graph because the sample was too small to meet standards for reliability or precision. The Child and Adolescent Health Measurement Initiative (CAHMI) advises using caution when interpreting categories that contain less than 50 cases. Percentages are weighted.

Analysis of OCCYSHN's needs assessment surveys yielded similar findings. Parent, care coordinator, and medical provider respondents to OCCYSHN's surveys identified respite care as challenging for families of CYSHCN to access (see Exhibit 13 above). In addition, 24 percent of family survey respondents identified quality respite care as 1 of 3 things that their family most needs but has difficulty obtaining. Respite care was the third most popular priority area when CaCoon staff voted on priority issues to address within their community. One CaCoon nurse noted that families with a child with an autism diagnosis have an even more difficult time finding respite care, especially if the child is Spanish speaking.

The nurse noted that a family member might be willing to provide respite but would need to be well-trained to meet the child's needs. This situation also would require that there were trainers available to train the family member, and there were none in her community. In another county, a nurse described that parents whose child is receiving DD services have to recruit their own respite care provider. Often the person recruited is a family member or friend with no criminal history. The individual has to undergo a background check and be fingerprinted. Approved background checks are only valid for a certain period of time. In some cases the approved background check has become invalid because too much time has passed – due to DD backlog – and then the potential respite care provider has to undergo another background check. This nurse noted that respite care providers can be easily overwhelmed by care needs and noted that children with behavioral issues are particularly challenging for respite care providers.

In much of my community, there is no respite care. For example, a single mom has 4 kids under the age of 5. This mom has not slept more than an hour in 2 years, because of the kids' special needs. There is no child care that would take any of her kids at her income level, and they don't qualify for DD services. They are right on the edge: if they make less money, and their kid is more disabled, they could qualify.

--CaCoon Nurse

Key stakeholder panel members agreed that respite care is challenging for families to access. Panelists also identified supports needed by families, such as services for genetic conditions, mental health

services, medical homes, and coordinated care. Family members need these services in addition to their CYSHCN but these services are not always covered by insurance plans for family members. Panelists noted that “family-centered care” encompasses families being able to access these services.

The needs of families of CYSHCN extend beyond respite care and family mental health and genetic counseling services. Findings from the 2011-2012 NSCH survey also showed that 38 percent of Oregon parents of CYSHCN reported that it was “very often” or “somewhat often” very hard to get by on their family’s income to cover the basics like food or housing, in contrast to 27 percent of parents of non-CYSHCN. Similarly 21 percent of CYSHCN families reported having problems paying or were unable to pay for their child’s medical bills, compared to 10 percent of non-CYSHCN families. Results of the Oregon Home Visiting Needs Assessment showed that the following were among the top 10 services that parents of young children with special health care needs identified as most difficult to obtain: housing assistance, job search help, job training/education help, child care, transportation help, adult dental care, adult mental/behavioral health services, domestic violence/sexual violence help, health insurance/medical care, and cash assistance (Oregon Health Authority, 2012). Results of the Child Family Survey (part of the National Core Indicators Project) indicated that 65 percent of family respondents reported that there are other services that their family needs that are not currently offered or available (Human Services Research Institute and National Associate of State Directors of Developmental Disabilities Services, 2014).

Twenty percent of OCCYSHN’s family survey respondents also reported that supports, such as activities with other families that have children with disabilities, coaching on how to get around on buses, help shopping, housing and homelessness services, parent or sibling support groups, sleep, and time to relax, were 1 of 3 things that their family most needed but was difficult to obtain. Medical providers reported that obtaining supports (e.g., income support, peer support, parenting resource supports) was difficult for families of CYSHCN (see Exhibit 13 above). Coordinators also reported that families of CYSHCN experience challenges accessing other families of CYSHCN with similar diagnoses (see Exhibit 13 above). Exhibit 19 presents themes that arose in the facilitated discussions with CaCoon nurses and examples of how these support needs manifest in their communities.

Exhibit 19. Family Service Access Challenges According to CaCoon Nurse Experiences

| Family Support Type |
|--|
| <p>Basic Needs</p> <ul style="list-style-type: none"> Families need food, heat, housing, water, and telephone service. When families are worrying about meeting their basic needs, they do not have enough capacity left to figure out how to get their child to an audiologist or worry about preventive health care. Families ability or not to meet basic needs affects the health of the children. |
| <p>Home Health Care</p> <ul style="list-style-type: none"> Some nurses get requests for helping families do IVs, infusions, and other skilled services for their child, but there are no such services. |
| <p>Local transportation</p> <ul style="list-style-type: none"> Families in rural areas need transportation for groceries. Public transportation in one rural area costs \$15 for one person each way; this is expensive when a single parent needs to take 2 children to the store. In many rural areas public transportation does not exist. A new bus line stops running by 7pm, which inhibits clients’ ability to attend feeding classes. <i>“I have several clients who don’t have vehicles; they walk everywhere. That is okay in nice weather, but what about in the winter in snow – they are pushing a stroller through the snow. Families may</i> |

Family Support Type

have one car, and the dad has [to use it] to go to work. What happens when the baby gets sick? The mom gets the stroller and walks to the ER.”

- Families with youth with disabilities need vehicles that have good gas mileage and can fit their child’s wheelchair.

Other

- A network of families with children with similar diagnoses is needed to provide parents with support within their county.
- Relief nursery is a wonderful resource and available for any family if DHS has slots in one county, but there is a long waiting list. In another county respite is only available to families who have DHS involvement.
- Smaller counties do not have lactation specialists.

Two-thirds of family survey respondents who needed child care indicated that it was difficult to obtain (see Exhibit 13 above). CaCoon public health nurses in Bend, Pendleton, and Roseburg, and key stakeholder panel members also identified child care as a challenge for families of CYSHCN to obtain. As discussed previously, these families can need child care for siblings of their CYSHCN to enable a parent and the CYSHCN to travel to health care appointments. In addition, families may need child care for their CYSHCN. CaCoon nurses in some Eastern Oregon counties identified access to quality child care as nearly impossible to obtain for all families, especially those of CYSHCN. Nurses said that parents might have to drive long distances to obtain child care, and the care still might not be of high quality. Nurses in eastern Oregon also said another challenge is that there are children who are too old for day care but are not yet old enough *“to stay on the ranch by themselves.”* These nurses said that there are few after school programs – typically programs are for athletes – and CYSHCN cannot go to the Boys and Girls Club. A nurse from southern Oregon said that, *“Child care for CYSHCN is really hard, and quality child care for a child with medical issues is very hard.”* Public health nurses from one county said that their office is discussing the ethics of encouraging mothers to go back to work – to gain economic self-sufficiency – when there is no, or substandard, child care available. Nurses in southern Oregon reported that *“sometimes the family is forced back into poverty if mom has to quit her job to care for her child.”*

Key stakeholder panel members also noted that families need help learning how to access various services that their child needs, and importantly, how to advocate for their families. Panelists noted that not all families are able to tell providers what they need, and providers often assume that everything is fine when it is not. One panelist suggested that it is very important, particularly for rural families, to have *“families coaching families so that they know what to ask for, they know what’s available...”*

For the 2014-2015 Title V Block Grant needs assessment, OHA’s review of 53 county health assessments found that CYSHCN family support was cited in 22 assessments. Its partner survey showed that out of 29 issue areas, CYSHCN family support was ranked 4th in terms of impact on the health of the respondent’s community, 12th in terms of its importance for addressing equity, 21st in the amount of time and resources currently being applied to the issue, and 9th the issue’s potential for leveraging state resources.

Social interactions for family and individuals with special needs are sorely lacking. A volunteer force of people trained to interact appropriately would be a great asset for everyone. – Family Member of CYSHCN

We also really need respite care so that I can get things done for my family during the day when no one else is home. I have to stay home from work to give my child care because she has CP and uses a feeding tube, and she also needs consistent attention so she does not choke or have any trouble breathing. This makes it hard to cook/clean/do anything else when she is awake! – Family Member of CYSHCN

System of Services for CYSHCN Findings

Both our quantitative (survey) and qualitative data collections sought to identify gaps or challenges in the systems of services for CYSHCN. In addition to challenges, however, we also sought to identify system strengths and opportunities on which to build. The section begins by describing challenges identified in the system of services for CYSHCN and their families. The section concludes with a description of the strengths within the system.

System Challenges

Findings related to challenges with Oregon's system of services for CYSHCN were derived from the OCCYSHN medical provider, care coordinator, and family surveys, as well as OCCYSHN's key stakeholder panel and CaCoon regional meetings. System challenges are described below by the following topics: human resources, policies, and service delivery system.

Human Resources

While discussing access to care issues for CYSHCN and their families, key stakeholder panelists reported system challenges that clustered into 2 groups: professional development needs and workforce shortages.

Professional Development Needs

Panelists identified the following as professional development needs of various types of professionals who care for CYSHCN.

- Health care providers need training in family-centered care practices and meeting families where they are. Providers need to ask youth and families questions like, "What is your highest priority need right now, what's your greatest challenge, what's most difficult for you about getting through the day?" Based on families' responses, providers can then develop an approach that aligns with the families' needs.
- Providers need more professional development on mental and behavioral health needs. Panelists noted that providers tend to think that youth with developmental disabilities do not have behavioral health challenges beyond their developmental disability (DD), and thus attribute challenging behaviors to DD and ultimately ignore the behavioral health challenge. Families with children with these conditions are left with unmet care needs.
- Panelists reported that there are some great community-based resources for CYSHCN and their families, but health care providers often are not aware of these services to be able to refer families of CYSHCN to them.
- Panelists stated that an increasing number of CYSHCN and families identify Physician Assistants (PA) as their primary care providers, and more outreach needs to be done to include PAs in conversations about CYSHCN.

Workforce Shortage

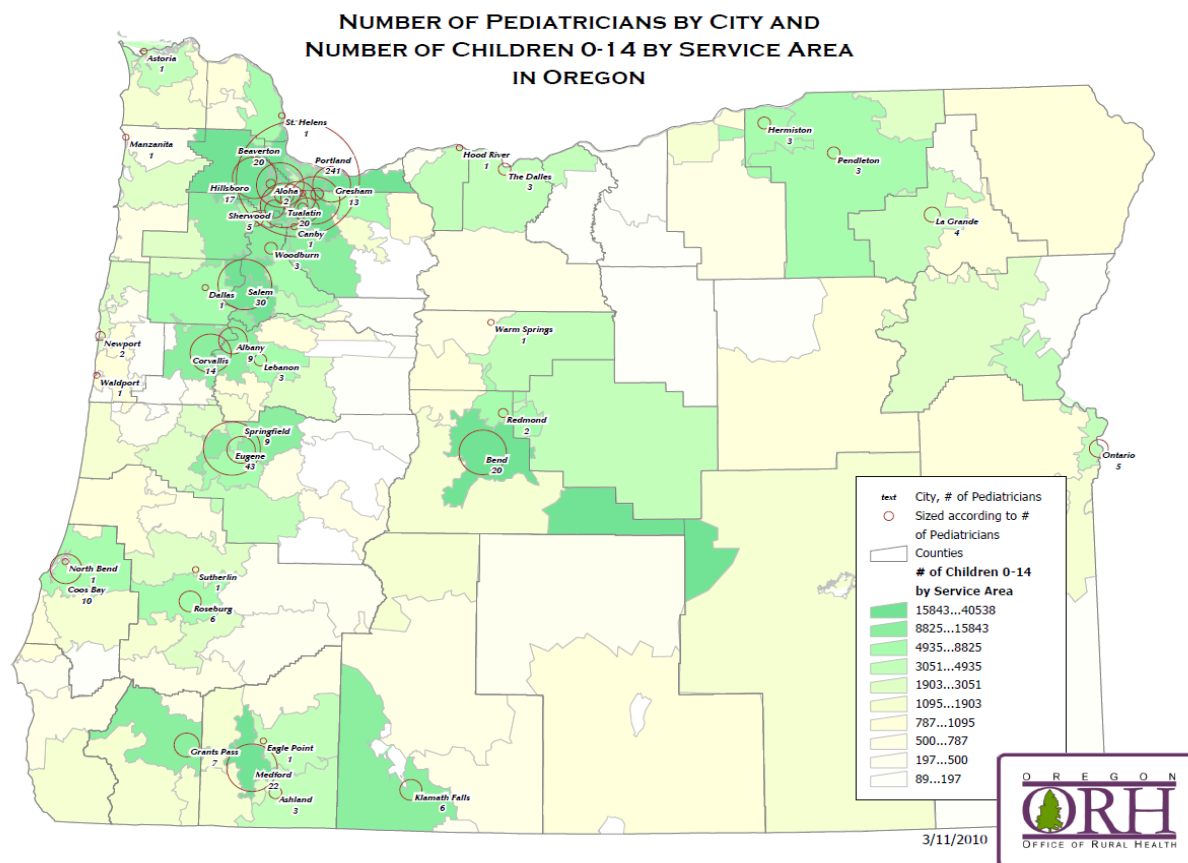
OCCYSHN asked medical providers and care coordinators, who responded to our survey, what, if any, provider shortages exist in their areas. These providers most frequently identified a shortage of mental health professionals and respite care providers in the geographic areas in which these professionals work (see Exhibit 20). Further, these responses were consistent across both providers and care coordinators. In addition, 50 percent of care coordinators reported a shortage of dentists; 45 percent reported a shortage of care coordinators, occupation/physical/speech therapists, and public health nurses. Medical providers least often reported that there were a shortage of chiropractors (1) and naturopaths (2). Care coordinators least often reported a shortage of chiropractors (5.4%).

Exhibit 20. Most Frequently Reported Provider Shortages

| Providers (n=26) | Coordinators (n=54) |
|---|---|
| <ul style="list-style-type: none"> • Psychiatrists (17) • Counselors/therapists (15) • Respite care providers (15) • Psychologists (12) | <ul style="list-style-type: none"> • Counselors/therapists (70%) • Psychiatrists (68%) • Psychologists (66%) • Respite care providers (63%) |

Members of our key stakeholder panel said that pediatricians, in general, are better attuned to the needs of CYSHCN than family practice physicians. Three of the 26 medical provider respondents reported a shortage of pediatricians, and 3 reported a shortage of family physicians. In contrast, 40 percent of care coordinators reported a shortage of family physicians, and 29 percent reported a shortage of pediatricians. Analysis of 2009 data by the Oregon Office of Rural Health showed that almost no pediatricians practice in eastern Oregon, as shown in Exhibit 21. This map further suggests that families living in most areas of our state lack ready access to a pediatrician.

Exhibit 21. Number of Pediatricians by City and Number of Children (0-14 years) by Oregon Office of Rural Health Service Area, 2009



sources: Oregon Board of Medical Examiners 2009, Claritas 2009

During the facilitated discussions with CaCoon public health nurses, they described a general lack of providers in rural communities, which necessitates travel for many of the families with whom they work. Nurses often stated that services that were identified by survey respondents as “able to access well” (see Exhibit 12 above) are not available in their communities. CaCoon nurses said many of those services are easier to access in more populous areas of the state. Nurses working in rural areas also described that there are some service providers that limit who they will serve (e.g., not serving families that live outside of their geographic region), which creates further access issues when families have to travel outside of their communities to seek care.

Key stakeholder panelists stated that workforce shortages exist generally within Oregon and particularly within rural communities. Panelists emphasized that providers are concentrated in areas with larger populations, which results in service access challenges for families living outside of those areas. Panelists stated that there are a small number of developmental pediatricians in Portland and Eugene, and none anywhere else in the state. They also reported that there are many job openings in rural

We have a very part-time physician who sees [CYSHCN]. We have a 0.4 FTE nurse. I think the need is greater than the ability to serve...
-- Key Stakeholder Panelist

communities in eastern Oregon, but the positions are not being filled. For example, panelists described a shortage of providers to work with the many families in eastern Oregon who have children with autism. Panelists stated that when the state initiates reimbursement for Applied Behavior Analysis (ABA) there will be a shortage of providers in eastern counties. Families will be excited about the service but will find out that they have to wait 6 months to see a provider located in Portland. As a result, both families and providers will give up trying to obtain the service for their child and lose “faith in the system.” Panelists also specified that there is a lack of an entity or organization for nursing delegation; that is, an organization that identifies nurses to provide the staff of non-medical settings (e.g., child care, school, transportation) with care training.

Panelists stated that because of the lack of providers in rural areas, or lack of providers with appropriate knowledge and experience working with CYSHCN, that children can go years without receiving a correct or complete diagnosis(es). Panelists also agreed that the approach to providing services in rural communities is a system inadequacy. For example, participants stated that locating a provider in Bend to serve central Oregon is inadequate because families still have to drive 100 or 150 miles to access the service. One participant stated, “It’s like saying, ‘well, you live in Eugene. Of course you can go up to Portland.’” These provider shortages also contribute to families having a long wait time before they are able to get an appointment for a provider.

[Our county] has one audiologist for the entire county. There is a 6-9 month waiting list...
--CaCoon Nurse

CaCoon nurses often noted that providers or specialists visiting their communities on a regular basis (e.g., once or a few times per month) either is or would be helpful to the families they work with. Regular visits to the community promote a sense of consistency and familiarity. CaCoon nurses suggested that it is important for the visiting provider to demonstrate investment in the community, have access to or possess knowledge of local resources that families will need to address their issues, and follow up with families to ensure that their recommendations or plans are implemented with the primary care provider.

CaCoon nurses also observed that three key systems serving CYSHCN – education, primary care, and public health – are all short-staffed and could use more “qualified trained staff to service more families.”

Examples of challenges to the education system included Early Intervention (EI) being over-burdened and consequently requiring time to return phone calls (EI staff have 14 days in which to return calls), some school districts no longer providing speech therapy or audiology services, and teachers not being able to meet the needs of children with autism spectrum disorders or behavioral issues, which many CYSHCN now have. A nurse said, “It takes the entire teacher’s time with these ‘problem kids,’ and they don’t have the skills to deal with [the issues].”

I’ve heard families say that there are providers who have started their professional careers in Bend, [that the providers] are contracted to come here. Once their contract is up, [the providers] leave the rural area and go somewhere else. Families felt ditched that [the providers] would come and just leave.
--CaCoon Nurse

Of the public health system, CaCoon nurses discussed their inability to market themselves and build new relationships with providers because their office would not be able to take on the potential additional workload such referrals likely would produce. They discussed the challenges of recruiting nurses into the public health workforce; Spanish-speaking public health nurses are particularly needed. A key challenge is

that the salaries of public health nurses are substantially less than those of nurses working in hospitals or clinics. Staff noted that new nursing graduates going into hospitals are making more money than the CaCoon nurses currently are, despite the CaCoon nurses having worked for as many as 40 years. In addition, hospitals provide a better schedule, such as 12-hour shifts for 3 days and then home for the remainder of the week. CaCoon nurses living in rural areas also talked about their service reimbursement for a home visit not including travel time; rural home visiting nurses cannot see nearly as many clients in a day or visit their clients as often as home visiting nurses living in more populous areas because their drive times can be substantially longer (e.g., 60 miles). Some CaCoon nurses noted that they are closer to CaCoon clients in neighboring counties than the CaCoon nurse living in those clients' county, but the closer CaCoon nurse cannot serve neighboring county clients because county governments do not have agreements on how to address these jurisdictional boundary issues.

...the wait list for therapy is extremely frustrating. There are not enough providers to handle the masses of children with special needs so my child and hundreds of other children get wait listed for therapies and treatment they need. Anyone who has any knowledge of autism knows early intervention is key. I think my son would be much more prepared for kindergarten and first grade had he been able to get into therapy sooner... – Family Member of CYSHCN

Policies

Key stakeholder panelists described several policies that prevent families from being able to access services for their CYSHCN. Several of these policy-related issues pertain to unintended consequences resulting from health care transformation. Policies for CYSHCN transportation and patient confidentiality practices also inhibit provision of care.

Health Care Transformation and Health Insurance

Coordinated Care Organizations (CCO) have latitude to determine what services are reimbursed in their catchment area; this policy results in some services or supports being available to families in one catchment area that are not available to families in different catchment areas despite both families being served by the Oregon Health Plan (OHP). In addition, panelists described that some CCOs are more difficult to obtain approval from for health care supports, such as mobility aids, than others.

Similarly, private insurance plans present access challenges because different plans also have the latitude to determine what services are reimbursed for their members. Panelists stated that translating services for CYSHCN from OHP to commercial insurance plans is challenging and a limitation. For example, CaCoon nurses described that “progressive” mental health programs are available to CYSHCN covered by OHP that are not available to those with private insurance. Families with private insurance have to show up on the day the program is offered and wait to see if they can be seen, and this is further challenging because “no parent with a CYSHCN can wait in a long line hoping to get in.” Panelists stated that these services are a smaller percentage of the costs for

So for instance, with regard to genetic services, the Health Evidence Review Commission has a great algorithm that was developed about what testing should be covered for kids with certain diagnoses, but the individual plans don't necessarily follow those guidelines... I think we could all agree that kids who have certain diagnoses should have certain tests to get an etiologic diagnosis, but it's this policy issue ... the state says there's evidence for this [practice], so this should be done; [however] it's not being done... I don't really understand why it's like that.

-- Key Stakeholder Panelist

the commercial insurance population, and thus, the motivation to change insured services is low because it is not in the insurer's financial interest.

CaCoon nurses also stated that OHP does not cover certain specialty health care services or genetics testing. Key stakeholders stated that professional guidelines exist that detail the circumstances in which particular types of care should be provided to children with specific diagnoses. However, CCOs do not necessarily follow these standards. Guidelines like these are intended to be a "floor" (a foundation from which to build better practice). Panelists did not understand why the CCOs are able to ignore these guidelines.

CaCoon nurses also talked about the access challenges that can result from the jurisdictional boundaries of CCOs. Some families live closer to providers located in Idaho or California, but OHP does not typically reimburse for services provided by health care providers located out of state. For example, some families of CYSHCN live closer to Boise, and thus it would be easier for families to travel there to receive care; however, OHP will not reimburse for those services. Another nurse noted, however, that in southern Oregon, OHP was reimbursing some services from California providers.

Panelists and CaCoon nurses identified reimbursement challenges that also limit families' ability to access needed services for their CYSHCN. That is, panelists understand that reimbursement rates from OHP are insufficient, or are perceived by providers as being insufficient, to cover providers' costs. This deficiency (whether real or perceived) results in providers not serving families who are insured by OHP, which contributes to provider shortages (as described previously). Families consequently experience unduly long wait times (e.g., 2 months to 1 year) to see a provider. CaCoon nurses across the state described that families' ability to access a dentist in a timely manner, or at all, is made more difficult if the family has OHP insurance, because fewer providers accept OHP. OHP has increased coverage for dental services, creating greater demand and thus longer waits for those providers who do accept OHP.

Insurance plans also do not reimburse providers for their time using technology to communicate with patients. For example, providers who communicate with families of CYSHCN on the phone or FaceTime cannot bill for this time. Using technology could expand access to services, particularly for CYSHCN living in rural communities, if insurance plans were willing to reimburse for provider time.⁷

Transportation

Transportation policies also challenge families' ability to access services for their child. No transportation support services exist for families who are not insured by OHP. Families who are insured by OHP do have transportation services. However, as discussed previously in the Access to Care section of this report, families experience myriad challenges with use of these services. One challenge that relates directly to policy is that transportation services only allow 1 parent and the child with the appointment to travel; siblings and other parents cannot. This policy creates a burden for the parent to find childcare for siblings and inhibits both parents from interacting with and learning from their child's provider(s).

Patient Confidentiality

Panelists identified the Health Insurance Portability and Accountability Act (HIPAA) as a barrier to communication for care coordination purposes. Panelists stated that it is difficult to create a HIPAA

⁷ Eighty-three percent of respondents to OCCYSHN's family survey reported keeping in touch with their child's provider by telephone; 25 percent reported by email.

release form that permits communication between individuals working for different entities that care for CYSHCN. Panelists noted that this challenge seems particularly acute when attempting to share information between primary care, education, and mental health. Panelists perceived that mental health providers often feel that there is no way to share information about CYSHCN; panelists described this as “a silo that you cannot penetrate.”

Service Delivery

The types of service delivery system gaps identified by panelists included a lack of culturally responsive services and poor communication with families about their service options.

Cultural Responsivity

The racial background of Oregonians is predominantly White, non-Hispanic (77.5%; U.S. Census Bureau, 2015). In 2011, the Oregon Department of Administrative Services, Office of Economic Analysis reported that the growth rate of minority racial groups outpaced corresponding national rates. The office also found that the population of Hispanics, in particular, is growing rapidly, although the state remains one of the least racially diverse in the country (Oregon Department of Administrative Services, 2011).

The California Department of Developmental Services (1997) defined a culture group as

people with common origins, customs and styles of living, who share a sense of identity and language. Their common experiences shape their values, goals, expectations, beliefs, perceptions and behaviors. People belonging to a unique racial, ethnic, or religious group typically share a similar culture (p. 2).

Key stakeholder panelists described a diverse range of African, Asian, and Slavic cultural groups that their agencies encounter. Panelists also reported a dearth of services that are culturally or linguistically responsive for CYSHCN. CaCoon nurses in the Bend regional meeting identified a need for culturally responsive services in areas of the state that employ seasonal migrant workers.

Panelists underscored the importance of families being able to communicate with their child’s providers. Although translation services are helpful, having providers who can communicate directly with the family in their language and have materials in their language will “open [families] up to be empowered to manage [their] family’s needs and access providers like [they] need to.” In addition, panelists described the importance of understanding a family’s culture, whether the culture is based on ethnicity, education, or socioeconomic status. Because cultural expectations or norms are a routine aspect of a family’s experience, families may not think to communicate these to a provider. Alternatively, families may be reluctant to communicate about these expectations and norms because they anticipate the provider will not understand. Thus, a provider who can be aware that cultural differences exist will better serve families with whom they work. The California Department of Developmental Services (1997) explained cultural responsivity as:

The culture in which a person lives impacts their attitudes, thoughts, feelings and actions, whether they have a developmental disability or not. Being able to bridge the gap between our own cultural background and the cultural background of the people we serve will: strengthen, support, and facilitate our role in assisting people as they plan their preferred future. There are many benefits in being culturally responsive. Among the benefits is the ability to: · foster more understanding of the person and how the person

operates, feels, and the ways in which they live their life, · let people know they are thought of as individuals, as human beings, · effectively communicate culturally sensitive choices and their consequences and · be aware of many possibilities and respond appropriately. The sum of these positive benefits is the ability to be responsive to the needs of individuals and their families as they make choices and plans, which often are based on a framework influenced by their cultural background (p. 3).

The benefits of cultural responsiveness are apparent in an example shared by a key stakeholder panelist in working with an African family. More than once, the family brought their child to the hospital with fractured bones, which resulted in the involvement of Child Welfare and, later, allegations of child abuse. Once a culturally-specific family liaison started to work with the family, however, the liaison was able to obtain background information, from which it was discovered that the child had a rare bone condition. The bone condition had caused the fractures. After correctly diagnosing the condition, appropriate treatment was provided to the child. The panelist stated that, *“this family went through the wringer”* and the child received inadequate treatment because the providers and family were not communicating effectively.

Communication with Families

Panelists stated that in their experience providers can offer care and service options, such as longer appointments or pre-visit planning, but families often do not know that these options exist and therefore cannot use them. More effective communication about these options could increase families' awareness and use of them. Communication about services could come from providers but also could come from nurse home visitors, family navigators, or CCO intensive case managers.

Sometimes [families] don't know what they don't know.
-- Key Stakeholder Panelist

System Strengths

CaCoon nurses and key stakeholder panelists were asked to describe aspects of the system that worked well or areas that could be built on to better serve CYSHCN and their families. Thematic analysis of these qualitative data produced one broad theme – integration of care for CYSHCN – and examples of “bright spots” in various communities. This section concludes with current systemic efforts that are complementary to improving the system of care for CYSHCN.

Integration of Care

Panelists stated that primary care transformation could provide the foundation to ensure that CYSHCN treatment teams better match children's needs. Panelists described that more clinics, including pediatric clinics, are embedding behavioral health counselors in their clinic (and noted that the counselors may not work full time). Panelists stated that physical health care professionals see the value in including behavioral health professionals in their clinic and expect this practice to grow. Panelists also noted that integration of dental care into medical health is a positive development.

Systems are...beginning to communicate and not act so much in silo anymore.

We're in an age of increased awareness.

--Key Stakeholder Panelists

Panelists reported that cross-system communication is *beginning* to occur. Panelists acknowledged that current efforts at cross-system care coordination are lacking; however, they perceived that primary care providers (particularly pediatricians) are beginning to understand the importance of coordinating across systems, and some provide care coordination services in their

practices. Panelists perceived that the state is supporting wraparound models of care. In these models all systems that work with a family and their children come together to form one plan that includes all the family's needs. Such a plan is based primarily on the family's identification of their needs. Panelists hoped that such support would extend to care coordination efforts for CYSHCN. Panelists stated that Early Learning Hubs are beginning to attempt to better coordinate the education system with the health care system for young children.

Panelists also described the beneficial work of the Community Connections Network (CCN).⁸ Panelists called this work “transformational” for families who have access to a CCN team and the ability to get to the team. They described situations in which families' needs were immediately met once they began to work with a CCN team. Panelists wished for CCN to be “cloned.”

“Bright Spots”

Opportunities in the system of services for CYSHCN, not related to integration of care, emerged from the CaCoon regional discussions and OCCYSHN's key stakeholder panel. These “bright spots” are listed as follows.

- **Community Capacitation Center.** Panelists identified that the work of the Community Capacitation Center in Multnomah County (<https://multco.us/health/public-health-practice/community-capacitation-center>) and its community health workers seeks to ensure that the voices of families of diverse cultural and linguistic backgrounds are heard and their needs supported and advocated for.
- **Developmental Disability (DD) caseworkers.** Panelists reported that, “*there are some amazing developmental disability caseworkers around the state.*” Panelists acknowledged that not every DD caseworker was effective, but some “change the lives” of the families with whom they work. Panelists observed that it is sometimes by luck that families “...stumble on somebody who can really help them learn how to self-advocate and access things on their own...”
- **Camp Elderberry.** One CaCoon nurse mentioned this day camp as a “bright spot” in the system. Camp Elderberry is a structured day camp for children and young adults with Autism (<http://campelderberry.com/about.html>). The nurse noted, however, that cost and transportation present barriers to some children with Autism being able to participate.
- **Family network providers.** Panelists noted that the number of formal family network providers has increased. These providers facilitate families learning about their child's health condition(s), options and treatment, other families and being able to educate one another.
- **On-call mental health providers.** One CaCoon Nurse reported that a strength in their community is the availability of on-call mental health providers. This is a valuable resource especially in crisis situations.
- **Preventive health care, including public health.** CaCoon nurses reported that access to preventive health care has improved due

We get our training on how to do fluoride from OHA. It was a well-publicized, free training. They gave us all the materials for free to use on the clients, and there was no paperwork... ‘First Tooth’ is a bright spot. – CaCoon Nurse

⁸ Community Connections Networks (CCN) are community-based multidisciplinary child health teams that meet to plan care for CYSHCN with unmet needs. Teams include representatives from health care providers, public health, education, families of CYSHCN, social services, developmental disabilities, mental health, and others.

to implementation of the Affordable Care Act. CaCoon nurses identified that public health services, such as providing fluoride treatment and immunization programs, through the local health department are working well in their communities. Nurses also spoke positively about fluoride treatment training provided by the Oregon Health Authority.

- Public health home visiting programs.** Panelists stated that public health and community-based nurses who conduct home visits are valuable for families of CYSHCN. Panelists noted that families of CYSHCN use emergency departments when they are unable to get other appointments. Nurse home visitors can help families to understand other services that exist outside of emergency departments and coach the families on how to navigate the system, helping them make appointments and arrange transportation. Panelists also reported that nurse home visitors help physicians by being a window to the child and family's home environment. CaCoon nurses reported that the CaCoon as a whole is a "bright spot" in the system. They carry out care coordination utilizing a holistic approach to care; that is, addressing all of the family's needs including those outside the realm of health care. CaCoon Nurses are able to meet families where they are, identify their needs, and make those valuable connections for families.

[CaCoon] public health nurses are doing the care coordination. We have a great partnership with the ESDs, EI program... The public health nurse is usually always at every IFSP/ IEP meetings, and on the phone with docs to get care for their child. Public health nurses also help families get access to housing and help them get food, box meals, and everything in between.
–CaCoon Nurse
- Screening Tools and Referral Training (START).** Panelists also stated that the work of START (file:///C:/Users/martial/Downloads/Year_5_Annual_Report.pdf) could be built upon. Thus far, good progress has been made toward universal screening; however, panelists noted that referral from screening is "just the tip of the iceberg." The next piece is to ensure that families are getting the services they need, that services are coordinated and of high quality, and that families stay engaged.
- Oregon Commission on Autism Spectrum Disorder (OCASD).** The inception of the OCASD and changes to the services covered by insurance has helped address the needs of children with ASD and their families. Panelists noted that the state now recognizes Applied Behavior Analysis (ABA) as a treatment for Autism. There are not enough providers throughout Oregon, however, which will result in families being unable to access this service for their child.

There's been a lot of great work over the last few years, and more to come, around Autism.
-- Key Stakeholder Panelist
- Telemedicine.** Panelists noted that much is known nationally about how to use telemedicine, and momentum is building for use of telemedicine for services like genetic testing. Although telemedicine is not yet widely used within Oregon, knowledge and resources exist to make it a viable strategy for service provision.
- Transition to Adulthood efforts.** Panelists observed that with increasing frequency they come into contact with teenagers at Shriner's Hospital and Child Development and Rehabilitation Center (CDRC) who can speak knowledgeably about their conditions. Panelists observed that Shriners Hospital has a staff member who is dedicated to Transition to Adulthood and does amazing work. Panelists noted that this may result from providers listening to youth and talking with them about their conditions. Panelists also noted that schools that have capacity also are doing some good transition work.

- **Visiting providers to rural area clinics.** Providers from the metro areas such as those based in Portland and Eugene, travel to rural areas on a regular basis to set up short-term clinics for CYSHCN. This practice as a “bright spot” is dependent on the provider. Although, nurses from one county described challenges when the visiting provider is not a good fit or not invested in the community.

Complementary Systemic Efforts

For the overall Oregon Title V needs assessment stakeholder meetings OCCYSHN staff identified current efforts that address the National Priority Areas (Medical Home and Transition to Adulthood) and the 2010-2015 state priority areas (Access to Mental Health Services, Access to Specialized Health and Health-related Services, and Family Support) for CYSHCN. These efforts are listed by their priority area.

Medical Home and Access to Specialized Health and Health-Related Services

- OCCYSHN received 1 of 12 HRSA/MCHB funded State Implementation Grants for Enhancing the System of Services for CYSHCN through Systems Integration. The 3 year grant aims to achieve a comprehensive, coordinated, and integrated state and community system of services for CYSHCN. Its objective is to increase by 20 percent the proportion of CYSHCN who receive care through a medical home by 2017. OCCYSHN and OPIP are collaborating with state partners to implement the grant.
- The PCPCH Program seeks to develop strategies to identify and measure what a primary care home does, promote their development, and encourage Oregonians to seek care through PCPCHs. None of the program’s standards for PCPCH certification explicitly require addressing care for CYSHCN; however, CYSHCN are one example of how a practice could meet Standard 5.C, Complex Care Coordination (Oregon Health Authority, 2013).
- The foci of the Oregon Pediatric Improvement Partnership (OPIP) include implementation and enhancement of patient-centered primary care medical homes and use of practice-level findings to improve policy (Oregon Pediatric Improvement Partnership, 2011).
- The Community Connections Network (CCN) has 9 teams composed of education, health, and community services representatives that seek to improve local systems of care and ensure receipt of care.
- CaCoon is a statewide public health nurse home visiting program for CYSHCN and their families that includes the provision of care coordination. Promotoras work with CaCoon programs in 4 counties with high concentrations of Spanish-speaking families.

Access to Mental Health Services

- In 2009 the Governor created the Oregon Commission on Autism Spectrum Disorders (OCASD). In 2010, OCASD made 4 recommendations to the Governor that include early identification and immediate provision of services, service integration, and training of personnel statewide.
- In August 2013, Oregon passed SB365, the state’s autism reform bill, which establishes requirements for state-regulated health plans to approve and manage autism treatment, including Applied Behavior Analysis (ABA). An ABA Regulatory Board has been established within the Oregon Health Licensing Agency.
- The same legislation also funded the Early Assessment and Support Alliance (EASA), which provides information and support to Oregon youth who are experiencing symptoms of psychosis for the first time.

- In 2013, Oregon funded the Oregon Psychiatric Access Line about Kids (OPAL-K). This collaboration between OHSU's Division of Child/Adolescent Psychiatry, the Oregon Pediatric Society, and the Oregon Council of Child and Adolescent Psychiatry provides free, same-day psychiatric phone consultation to Oregon primary care clinicians. The goal is to reduce delays in diagnosis and treatment and enhance capacity for primary care practices to treat children with mental health conditions.
- The HRSA/MCHB funded Assuring Comprehensive Care through Enhanced Service Systems for Children with ASD/DDs (ACCESS) grant project supports building local medical-educational ASD Identification Teams and to improve medical home practices' delivery of comprehensive, coordinated health care and related services for children with ASD/DD.

Family Support

- The Oregon Family to Family Health Information Center employs parents of CYSHCN to provide information to families navigating the complexities of meeting their child's special health care needs. The Center is available to families statewide.
- 211info provides free information on over 50,000 programs in Oregon and southwest Washington.
- According to key stakeholder panelists, the Early Learning Hubs are increasing the availability of parenting classes and supports for all families, including those of CYSHCN.
- The Statewide Family Training Outreach Committee (SFTOC) was formed in 2013. It is a coalition of family groups, all of which conduct family training and outreach throughout the state. The coalition has made progress toward bringing more, and better-attended, family support activities to communities throughout Oregon.
- Swindells Resource Center provides resources, information, and education to parents and caregivers of children with special needs, developmental delays, or disabilities in Oregon and southwest Washington.
- Six family networks have been funded by the Oregon Council on Developmental Disabilities. Their purpose is to link families to the natural and supportive environments that exist within their communities.

Transition to Adulthood

- The Governor's Executive Order No. 13-04 focuses on improving employment services to individuals with intellectual and developmental disabilities (I/DD). This executive order is realized through the Oregon Department of Human Services' Employment First, which acknowledges that working age adults and youth with I/DD can work in integrated jobs (i.e., those located typical workplaces in the community with opportunities to interact with colleagues and customers without I/DD). In addition to DHS Vocational Rehabilitation and Office of Developmental Disability Services, the Oregon Department of Education and Oregon Council on Developmental Disabilities participate in implementing the executive order (Oregon Department of Human Services, n.d.).
- The Oregon Consortium of Family Networks has a Reaching Our Community Combining Our Strengths (ROCCOS) Family Network website. One of the website's goals is to help college students with disabilities get information and support to succeed in their academic career.

- Some families have served as mentors for others through the Oregon Family to Family (F2F) Health Information Center *Transition Stories*, which are health-focused “vignettes” about strategies to improve the transition process for CYSHCN and their families.

State Priority Areas

The Title V Block Grant requires states to identify 3 to 5 state priorities (in addition to their national priorities), which may focus on CYSHCN. As OCCYSHN’s key stakeholder panelists were asked for their recommendations for the national priority areas, they also were asked for their recommendations for state priorities for CYSHCN. They were also asked to explain the reasoning behind their recommendations. Panelists identified a range of issues (see Appendix C), which have been incorporated into the thematic categories discussed previously in this report. A dot exercise was used to gauge panelists’ interest in addressing each of the issues. The exercise showed that panelists had substantial interest in addressing the following: lack of reimbursement for services, disparities in access to services, mental health, and care coordination.

Discussion and Conclusions

As a requirement of the Federal Title V Block Grant, OCCYSHN conducted a needs assessment of Oregon CYSHCN and their families. The assessment sought to describe this population’s services and support needs and the strengths and the challenges of the system(s) that serve CYSHCN and their families. To meet these goals, OCCYSHN collected and analyzed quantitative and qualitative data from families of CYSHCN, young adults with special health care needs, and professionals and providers who work with CYSHCN and their families. The findings identified myriad challenges facing families of CYSHCN and opportunities for better integration of systems serving these families. Conclusions are organized by major topics that were identified at the start of the needs assessment and those that emerged from it.

Transition to Adulthood

Findings suggest that medical providers do not consistently address transition issues. Our results suggest that a lack of knowledge about transition care and planning for YSHCN is one reason transition is not addressed. In addition, it appears that there is a shortage of adult health care providers who are prepared to care for transitioning CYSHCN. Although efforts in the state focus on education and employment transition, no efforts are underway to address health and health care transition, which may impede CYSHCN from completing high school, attending college, or securing employment (DHHS, 2015). Further, transition efforts must address the needs of CYSHCN who will not have any independence from caregiving. Ideally, planning for health care transition would be incorporated into the implementation of medical home.

Medical Home

A key effort to increase medical homes in Oregon is the Patient-Centered Primary Care Home (PCPCH) program. The distribution of certified PCPCHs around the state is uneven. In addition, the program’s certification does not require that the practice meet standards specific to CYSHCN. Medical providers that responded to our survey, however, did report offering a variety of necessary service options (e.g., longer appointments, evening and weekend appointments) to the families of CYSHCN. Few family respondents reported that they often encounter problems (e.g., lacking insurance, inability to take time off of work) in visiting their child’s primary health care provider. A few problems (e.g., scheduling an appointment as quickly as needed, long waiting room waits before the appointment) were experienced at least

sometimes by a majority of responding parents. Providers not communicating their available service options that accommodate these families may contribute to families' experiencing these challenges. Most young adults that responded to our survey reported that their health care providers listen carefully to what they have to say and explain things in a way that is easy for the youth to understand.

Care Coordination

Care Coordination appears to be an aspect of medical home that is not well-implemented for CYSHCN. National survey estimates showed that nearly one-third of parents of CYSHCN with more complex health needs felt that they could have used extra help coordinating care among care or service providers. Similarly, OCCYSHN's family survey results showed that as many parents reported rarely or never receiving as much help as they wanted coordinating care as those who did. Professionals involved in care coordination perceive care coordination efforts as siloed and challenged. Communication and information sharing between providers and families is necessary for effective care coordination; but providers and coordinators identified the gaps in both as barriers to coordinating care. Professionals who work with CYSHCN and their families noted that it is particularly important for representatives of the primary health care, mental health, and education systems working with CYSHCN to coordinate their care. Improving cross-systems care coordination for CYSHCN will entail addressing patient confidentiality concerns, availability and compatibility of electronic health records, and health insurance coverage for time spent coordinating care by providers.

Findings also suggested that care plans are an under-utilized tool. Most families reported that their children did not have a care plan. Of those who did, only half reported that the plan had been shared with all of their child's service providers. In addition, providers did not report that they updated care plans as frequently as the National Consensus Framework standards suggest. Key stakeholder panelists suggested that families do not know to ask their providers for a care plan, and that the gap in utilization of care plans is likely more substantial than what is reflected in survey results.

Access to care

Findings from OCCYSHN's survey show that parents experience difficulties accessing specialty health care and family supports for their CYSHCN. Accessing behavioral and mental health services (including autism specific therapies), respite care, health supports (e.g., durable medical equipment, mobility aids, home health care, palliative care), specialty dental care, and specialty medical care were identified as challenging. Difficulties in accessing services may, in part, result from the type of insurance covering the child's health care. For example, key stakeholder panelists noted that insurance providers often will not reimburse for mental health services. In addition to insurance challenges, the location of and transportation to services arose as a key issue that inhibited CYSHCN access to services. These are discussed further in the systems section below.

Vulnerable populations and those who serve them have always been at the bottom of the distribution of resources and care. This has to change!
-CaCoon Nurse

Family Support

Across all data collections, participants identified respite care for families of CYSHCN as challenging to access. Health-related supports for family members of CYSHCN (e.g., mental health services, genetic services) and child care and material (e.g., housing assistance, income support) and social supports (e.g., peer support, activities with other families of CYSHCN) were identified as difficult to access.

Culturally and Linguistically Responsive Services

Results of our analysis of data collected from key stakeholder panelists and CaCoon public health nurses suggest that culturally and linguistically responsive services for CYSHCN are lacking. Although CaCoon programs in 4 counties work with Promotoras, OCCYSHN does not have a strong sense of the breadth of need for cultural brokers or the cultures for which brokers are needed. The availability of culturally responsive services is important, however, for ensuring equity in health care access and promoting health literacy among families of CYSHCN.

System Challenges

Results revealed myriad challenges within the system(s) serving CYSHCN and their families. These challenges inhibit families' ability to access care for their children. For example, workforce shortages exist, particularly among mental and behavioral health professionals, respite care providers, pediatricians in most areas of the state, developmental pediatricians, and dentists who are able to work with CYSHCN (and who accept OHP). Such shortages in rural areas require families to travel for their child to receive care. Travel time and costs burden families of CYSHCN, even when transportation is supported for children covered by OHP. In addition, the current health provider workforce needs training in family-centered care practices, mental and behavioral health needs and care, existing local resources that can support families, and cultural and linguistic competency. Given the findings on transition to adulthood and shared care planning, current providers are also likely to need training on these topics. Findings also suggested that the primary care, education, mental health, and public health workforce is overburdened, and that there are recruitment and retention challenges in rural areas for both private and public health care positions.

Policy-related system challenges also emerged from our data analyses. These challenges primarily related to unintended consequences resulting from Oregon's health care transformation. For example, CCOs have the latitude to determine the types of services that are reimbursed in their catchment area. Stakeholders told us that this policy results in some services or supports being available to families in one catchment area that are not available to families in different catchment areas despite both families being served by OHP. Similarly, private insurance plans also have the latitude to determine the services that are reimbursable for their members. Panelists shared that translating OHP services for CYSHCN to the commercial insurance population is difficult. Insurance companies have low motivation to change because CYSHCN health care costs are relatively small compared to the entire commercial insurance population. Public health nurses also identified that OHP does not cover some specialty health care services or genetic testing. Finally, stakeholders also noted that OHP's reimbursement rates are not sufficient to recruit the numbers of providers that are needed to serve CYSHCN.

Lastly, patient confidentiality surfaced as a policy-related system challenge that inhibits care coordination across systems of care. Stakeholders reported difficulties in creating a HIPAA release that permits communication between providers working for different entities. As previously stated, stakeholders noted the importance of coordination between primary health care, education, and mental health when caring for CYSHCN. The information-sharing barrier with mental health often feels particularly insurmountable.

System Strengths

Results from the key stakeholder panel discussion suggest that norms around integration and coordination of care have begun to shift. This shift is reflected, for example, in the inclusion of behavioral health counselors in pediatric practices. Panelists also perceived that some pediatric primary care

providers are beginning to understand the importance of care coordination and take steps to provide the service to families of CYSHCN. Panelists also perceived that the state is supportive of wraparound systems of care, which they hoped would extend to cross-systems care coordination for CYSHCN. In addition, CaCoon public health nurses and key stakeholder panelists identified a number of “bright spots” in the systems that serve CYSHCN. These bright spots included specific individuals (e.g., Developmental Disability caseworkers), specific programs (e.g., Camp Elderberry, Community Capacitation Center), and health care service sectors (e.g., public health).

Limitations

The results of OCCYSHN’s needs assessment provide valuable information to better understand the needs of Oregon CYSHCN and their families, and the dynamics within the system(s) serving CYSHCN that inhibit access to care. The results, however, cannot generalize to the population of Oregon CYSHCN and their families. Implementation of a research design that would have permitted such generalization was beyond the resources available for this project. OCCYSHN used a mixed methods design (quantitative and qualitative methods) to attempt to strengthen the needs assessment design, but as with any study, some limitations remain. An explanation of the limitations, and attempts to minimize them, follows.

No data source exists that identifies all Oregon CYSHCN. This necessitated that OCCYSHN use a snowball sampling approach for its survey data collection to identify families of CYSHCN and young adults with special health care needs. OCCYSHN’s partners and their networks helped identify people to participate in the survey. This sampling approach also was used to identify medical providers and care coordination professionals who serve CYSHCN and their families. This sampling approach results in a convenience sample, which does not permit generalization to the population from which the sample comes.

Demographic results of our family survey participants (see Exhibit 1) show that OCCYSHN survey respondents tended to be more well-educated, live in primarily metropolitan counties, and have a child identified racially as White and ethnically as non-Hispanic. Seventy-seven percent of parents who responded to OCCYSHN’s survey reported that they had a bachelor’s degree or higher. According to the Census Bureau, about 30 percent of Oregonians aged 25 years or older have a Bachelor’s degree or higher (U.S. Census Bureau, 2015). It is reasonable to assume that the perspective of families living in rural areas, families of color, or families with less formal education could differ from those of our survey respondents. In addition, a key stakeholder panelist observed that the needs assessment survey likely did not reach families who do not know how to advocate for their families’ needs, especially those living in rural communities, as they may not be connected with family networks. Therefore, survey results should be interpreted to reflect the experiences of those data collection participants. Despite these differences, however, survey results still showed that families of CYSHCN responding to our survey experience challenges.

OCCYSHN’s data collection with CaCoon public health nurses helped to broaden our perspective of the needs of families that may not have been well-represented in the family survey. CaCoon public health nurses work with families with demographic characteristics that generally differ from the survey family respondents. During the 2014 fiscal year, 92 percent of CaCoon clients were enrolled in Medicaid, 34 percent were Hispanic, and 10 percent had a non-White racial background (Oregon Center for Children and Youth with Special Health Needs, 2015). Therefore, although OCCYSHN did not collect data directly from these families, collection of data from CaCoon professionals provided OCCYSHN important insights into the experiences of these families. In addition, OCCYSHN will consider how to obtain information

directly from families of color and families living in rural and frontier areas in its ongoing Title V block grant needs assessment activities.

Family medicine providers are under-represented in the medical provider results. Providers who participated in the survey most frequently identified themselves as pediatricians. According to one key stakeholder panelist's experience, the care that family medicine provides for CYSHCN looks different from that provided by pediatricians in that family medicine is usually not as attuned to the needs of CYSHCN. Results from the key stakeholder panel may have provided some insight into how these results might differ; however, OCCYSHN will continue to consider how to obtain the family medicine perspective in its ongoing work.

The OCCYSHN surveys did not collect sufficient data about specialty health care (e.g., cardiology, neurology, pulmonology, etc.). OCCYSHN obtained broad information about specialty health care needs through an open-ended question, "What are the 3 things that your child or family needs most but has a hard time getting?" Thirty-nine percent of families reported a response that was related to specialty medical care. Although OCCYSHN had a number of staff and stakeholders (including family representatives) review its surveys in advance of administration, OCCYSHN was not able to conduct pretests with parents because of time constraints in the overarching needs assessment timeline. This oversight likely would have surfaced during pretesting. OCCYSHN will explore how to better understand these needs in future needs assessment data collections.

Conclusion

Many of the needs of CYSHCN and their families identified in the 2010 Title V Block Grant needs assessment persist. In 2010, these needs emerged from the needs assessment process:

- "Opportunities to receive health and mental health consultation regarding care of children and youth with special health needs
- Knowledge, skills, and confidence of parents in caring for children with special health needs
- Mental health for families and children
- Geographic limitation of many specialized services to metro areas
- Respite and qualified child care / after-school programs
- Transition to adult life, including adult health services, work and independence
- Respite care availability for care takers
- Gaps in early childhood services
- Collaboration across health, social and support services for children and youth with special health needs
- Access to adequate health care insurance coverage
- Information and navigational supports – including care coordination, case management, information that is in usable and accessible forms
- Financial supports – items not covered by insurance or other means
- Accessibility of health, social, and support services
- Communication between schools and services (physical and mental health services and other services)" (Oregon Office of Family Health and Oregon Center for Children and Youth with Special Health Needs, 2010, p. 29-30).

Addressing these persistent needs requires strategies that align with the 3 core functions of public health: Assurance, Policy Development, and Assessment (Schneider, 2011).

- Assurance.** To link CYSHCN and their families to health services (Schneider, 2011), better cross-systems coordination of services (including primary health care, specialty health care, mental health, public health, education, early learning, and community-based services) is needed. “Successful cross-system care coordination takes into consideration the continuum of health, education, early childcare, and social services needed to improve the quality of care for CYSHCN” (U.S. Department of Health and Human Services, 2014b, p. 4). The *Standards for Systems of Care for Children and Youth with Special health Care Needs* (VanLandeghem et al., 2014b) provides Oregon with a framework by which OCCYSHN and other state partners can begin to collaborate to improve the systems serving CYSHCN. To assure a competent public and health care workforce (Schneider, 2011), workforce development is needed in the areas of transition to adulthood, medical home for CYSHCN, and care coordination. In addition to the workforce gaining an understanding of these concepts and how to implement them to best serve CYSHCN, the workforce also needs to understand how to implement them in a culturally and linguistically responsive manner.
- Policy Development.** To address policy issues inhibiting CYSHCN access to care, community partners and stakeholders need to be identified and mobilized (Schneider, 2011). OCCYSHN’s current MCHB State Implementation Grant for Enhancing the System of Services for CYSHCN through Systems Integration provides such an opportunity. Key stakeholders in the systems that serve CYSHCN are being convened for this grant effort, which may provide an opportunity to address barriers to service access that are, for example, associated with insurance coverage.
- Assessment.** To well understand CYSHCN families who are culturally and linguistically diverse, OCCYSHN has further assessment work to undertake as part of its ongoing Title V needs assessment. OCCYSHN needs to consult with family representatives and community partners to learn how to best access members of these communities and collect data from them in culturally appropriate ways.

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Appendix A: Data Collection Methods and Analysis

Two key questions guided OCCYSHN's needs assessment. The questions were: (1) What are current needs of Oregon CYSHCN and their families, and (2) What are the challenges and strengths of the system of care serving CYSHCN? OCCYSHN used a mixed methods design to answer these questions. Separate quantitative and qualitative methods were used to corroborate findings and offset limitations inherent in each method (Creswell et al., 2003). Within these broad questions, OCCYSHN staff identified a set of topics on which to focus its data collection: Access to Needed Services and Family Supports, Medical Home, Care Coordination, and Transition to Adulthood. Quantitative data used for OCCYSHN's needs assessment came from primary and secondary sources. Qualitative data came from primary data collections. This appendix provides greater detail on the collection and analyses of OCCYSHN's primary data collections.

Quantitative Data Collection and Analysis

OCCYSHN conducted surveys of 4 stakeholder groups: (1) families of CYSHCN who are between the ages of birth and 26 years of age; (2) young adults between the ages of 12 and 26 years of age who have a special health care need; (3) medical providers who serve CYSHCN between birth and 26 years; and (4) professionals who provide care coordination services for CYSHCN, between the ages of birth and 26 years, and their families. Survey items were informed by items used on OCCYSHN's 2010 needs assessment survey and existing national surveys (e.g., the National Survey of Children with Special Health Care Needs [NS-CSHCN], 2009-2010; Got Transition; Consumer Assessment of Healthcare Providers and Systems [CAHPS] versions 3.0 and 4.0 and the Children with Chronic Conditions item set), Alabama's Title V CYSHCN stakeholder surveys (young adult, family, provider), and the *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (VanLandeghem et al., 2014b). Surveys were reviewed by OCCYSHN stakeholders, which included community-based program staff, an epidemiologist, family navigators and family liaisons, and a physician. Professional translators translated the family and young adult surveys into Spanish. All 4 surveys were administered electronically via Survey Monkey. In addition, the family and young adult surveys were also administered by paper and returned by postal mail.

Because no lists exist that define the population of Oregon CYSHCN, their families, their providers, or their care coordinators, OCCYSHN relied on a snowball sampling approach to produce a convenience sample. A snowball sampling approach entails an evaluator identifying cases of interest from "people who know people who know people" who are rich sources of information for the data collection (Patton, 2002, p. 243). OCCYSHN staff contacted its partners by phone, email, or in person meetings to ask for their help in disseminating our surveys. Hard copy surveys and postcards with links to the electronic versions of the surveys were mailed or delivered to medical provider offices, youth-focused and parent events. Emails with links to the electronic surveys were sent to family and young adult organizations, community colleges, medical providers, care coordinators (in coordinated care organizations, public health departments, provider offices, clinics), schools, early education and child care centers, and youth camps. OCCYSHN requested that partner organizations disseminate the survey announcements on their listservs and Facebook pages. OCCYSHN also prepared a press release, which was disseminated to known news outlets in Oregon. OCCYSHN could not compute a survey response rate because the number of individuals who received the survey is not known. OCCYSHN collected survey data between July and October, 2014.

A doctoral student entered hard copy surveys returned to OCCYSHN into an Excel data file that mirrored the Survey Monkey Excel files. She verified entry for 100 percent of the survey responses. Data cleaning also was conducted by reviewing the raw frequencies for all survey items and correcting illogical values.

Descriptive statistics (frequencies and means) were computed for survey items. To determine whether survey participants (family, medical provider, and care coordinator) perceived health services and family supports as accessible or inaccessible, the first author first collapsed easy responses (e.g., very easy and somewhat easy) into one category and difficult (very difficult and somewhat difficult) into a second category. She then computed the differences in the percentage of respondents who reported a service was easy to access compared to the percentage of respondents who reported that a service was difficult to access. She identified natural breaking points in the distribution to determine meaningful differences. For example, Exhibit 22 presents results of the family survey and how ease and difficulty determinations were made. The first author used the same approach for the medical provider and care coordinator surveys for these items.

Exhibit 22. Percent Point Differences in Family Reports of Ease or Difficulty Accessing Health Services and Supports

| Health Service or Support | Easy (%) | Difficult (%) | Percent Point Difference | Interpretation |
|--|----------|---------------|--------------------------|----------------|
| Eye glasses or vision care (n=246) | 72.8 | 21.1 | +51.7 | Easy |
| Prescription medications (n=377) | 73.7 | 21.2 | +52.5 | Easy |
| Teeth cleaning, fluoride treatments (n=453) | 66.1 | 30.4 | +35.7 | Easy |
| Hearing aids or hearing care (n=62) | 58.1 | 33.8 | +24.3 | Easy |
| Speech therapy (n=360) | 49.5 | 45.6 | +3.1 | Split |
| Physical therapy (n=213) | 49.3 | 47.5 | +1.8 | Split |
| Genetic counseling (n=86) | 47.7 | 47.6 | -0.1 | Split |
| Nutrition counseling (n=231) | 46.3 | 47.6 | -1.3 | Split |
| Occupational therapy (n=359) | 46.0 | 50.7 | -4.7 | Split |
| Orthodontia or other dental care (n=253) | 43.9 | 50.6 | -6.7 | Split |
| Care to lessen symptoms (e.g. pain, fatigue, depression, inability to sleep or eat) of serious and chronic illness (n=207) | 40.6 | 52.7 | -12.1 | Difficult |
| Home health care (n=96) | 38.6 | 53.1 | -14.5 | Difficult |
| Durable medical equipment (n=158) | 41.1 | 56.3 | -15.2 | Difficult |
| Behavioral/mental services or counseling (n=338) | 39.6 | 55.3 | -15.7 | Difficult |
| Mobility aids (n=110) | 33.6 | 61.0 | -27.4 | Difficult |
| Child care (n=244) | 28.3 | 67.2 | -38.9 | Difficult |
| Substance abuse treatment or counseling (n=10) | 20.0 | 60.0 | -40.0 | Difficult |
| Respite care (n=257) | 25.3 | 72.0 | -46.7 | Difficult |
| Autism specific therapies (n=222) | 22.5 | 72.1 | -49.6 | Difficult |

Note: Family members were asked whether their child needed each of these services or supports. Those who did were then asked "How easy is it for your child to get that type of care?" A "+" sign before the percentage point difference indicates that participants tended to find this service or support easy to access; a "-" indicates that participants tended to find the service or support difficult to access. The percentage of missing responses is not included. With the exception of substance abuse treatment or counseling, less than 10 percent of respondents left these items blank; 2 of the 10 participants did not respond to the item.

Chi Square Subgroup Analyses

CaCoon public health nurses suggested to us that survey results describing the ease with which families access services and supports may differ depending on the type of insurance that the family has, and on whether the family works with a care coordinator. In addition, CaCoon nurses and key stakeholder panelists suggested that living in rural, or even suburban, areas also could challenge families' access. OCCYSHN used family survey data to examine these differences by computing Chi Squares between each of the services and supports presented in Exhibit 22 (with the exception of substance abuse treatment or counseling because of the small number of responses) and responses to the 3 survey items shown in Exhibit 23.

Conducting many statistical tests on the same set of data requires an analyst to use a more conservative statistical significance threshold (p value or alpha level) to minimize the likelihood of the analyst concluding that a statistically meaningful difference exists when, in actuality, such a difference does not exist (Type I error). Therefore, we adjusted the alpha levels using the Benjamini Hochberg adjustment (Benjamini & Hochberg, 1995). Results showed only 1 statistically significant finding, $\chi^2 (1, N=350) = 10.65$, $p = .001$. Phi coefficients were small and thus do not suggest that statistically significant results would be found in larger sample sizes; values ranged from 0.18 to 0.202 for those Chi Squares that had an alpha level less than 0.5. It may be, however, that more diverse sample would produce different results. As discussed in our limitations section, our survey sample did not well reflect diversity in education, ethnicity, geography, race, and socioeconomic status. In addition, as previously discussed, OCCYSHN's survey item asking whether someone had helped the family arrange or coordinate care in the past 12 months does not reflect the complexity of quality care coordination. A multi-dimensional measure would likely be more informative to these types of analyses.

Exhibit 23. Variables Used To Explore Subgroup Differences in Family Ease of Service or Support Access Survey Items

| Survey Item and Responses | Computed Categories Created for Comparison Purposes |
|---|---|
| In the past 12 months, did anyone help you arrange or coordinate care for your child? | NA <ul style="list-style-type: none"> • Yes • No |
| Currently, how do you pay for your child's health care? | Private insurance (Private health insurance or Tricare) only OR Private insurance <i>and</i> any combination of <ul style="list-style-type: none"> • Out of pocket • Friends or relatives |
| 1. Friends or relatives | |
| 2. Indian Health Services | |
| 3. Out of pocket | n=191 (34.5%) |
| 4. Medicaid, Healthy Kids, Oregon Health Plan | Public insurance (Indian Health Services; Medicaid, Healthy Kids, Oregon Health |

| | |
|--|--|
| (OHP) | Plan; Medicaid) only OR Public insurance <i>and</i> any combination of |
| 5. Medicare | <ul style="list-style-type: none"> • Out of pocket |
| 6. Private health insurance | <ul style="list-style-type: none"> • Friends or relatives |
| 7. Tricare (Military health insurance) | n=203 (36.6%) |
| 8. Other | Respondents could, and did, choose multiple response options. |
| 9. I don't know | <ul style="list-style-type: none"> • 15 respondents reported only out of pocket <i>or</i> friends and relatives. This could represent individuals in the most difficult financial conditions; however, the responses were excluded from analysis because there were so few cases. • 90 respondents reported public and private insurance only or with out of pocket and/or friends and relatives. It was unclear how to interpret this category; therefore, the responses were excluded from analysis. |
| What county are you living in now? | Rural (Baker, Gilliam, Grant, Harney, Jefferson, Lake, Sherman, Tillamook, Wallowa, Wheeler) n=11 responses |
| [Each of Oregon's 36 counties] | <p>Micropolitan (Clatsop, Coos, Crook, Curry, Douglas, Hood River, Klamath, Lincoln, Malheur, Morrow, Umatilla, Union, Wasco) n=82 responses</p> <p>Metropolitan (Benton, Clackamas, Columbia, Deschutes, Jackson, Josephine, Lane, Linn, Marion, Multnomah, Polk, Washington, Yamhill)^a n=411 responses</p> <p>This categorization is based on the U.S. Census Bureau's definition provided on the Oregon Office of Rural Health's website: www.ohsu.edu/xd/outreach/oregon-rural-health/data/rural-definitions/index.cfm. According to this definition a county that is not a metropolitan county is identified as rural.</p> <p>OCCYSHN separated micropolitan from rural counties for its analyses because examination of patterns of responses in the cross-tabulations suggested that families who reported living in micropolitan counties often reported that services were easier to access compared to families who reported living in rural or metropolitan counties. We computed Chi Square using the micropolitan and metropolitan survey responses because such a small number of surveys reflected families living in rural counties.</p> <p>Fifty of the 554 surveys included in the analysis (9%) left the county item blank.</p> |

Qualitative Data Collection and Analysis

OCCYSHN collected qualitative data through a key stakeholder panel, facilitated discussions with public health nurses, and open-ended survey items.

Key Stakeholder Panel

OCCYSHN hosted a panel discussion with 18 key stakeholders on December 10, 2014. Participants represented families of CYSHCN and the following organizations: APS Healthcare; Children's Health Alliance; David Douglas School District; Greater Oregon Behavioral Health, Inc.; Multnomah County DCHS/DDSD; North Central Public Health District; Oregon Child Development Coalition; Oregon Health & Science University and OHSU Child Development and Rehabilitation Clinics; Oregon Health Authority Early Hearing Detection and Intervention; Oregon Pediatric Improvement Project; Oregon Pediatric Society; and Providence Swindells Family Resource Center. OCCYSHN shared preliminary needs assessment results

with participants and asked stakeholders what results resonated with their experience and knowledge, and what unmet needs were not reflected in the results. OCCYSHN also asked participants to respond to the following questions: (a) Where is there capacity in the system to meet the needs of CYSHCN/What's working, (b) Where are there limitations in the system/Where is there a lack of capacity to meet the needs, and (c) How are Oregon's health care transformation efforts and innovation around early learning influencing the way services are delivered to or accessed by CYSHCN and their families? Lastly, participants were asked for their recommendations for national and state priority areas for CYSHCN for the Title V Block Grant for the next 5 years.

The discussion was electronically recorded and a verbatim transcript produced. The transcript was analyzed to identify categories of (a) systems challenges and gaps, and (b) examples of "bright spots" in which the system works well. A deductive and inductive thematic analysis was used to identify these categories. The analysis was deductive in that the categories of systems structures were identified in professional literature (i.e., human resources, policies, service delivery) and inductive in that the system structures discussed during the panel informed the category development. One analyst completed the initial coding. A second analyst, who also worked on the needs assessment, reviewed the panel transcript, emergent categories, and thematic analysis. Both analysts discussed and resolved discrepancies.

CaCoon Regional Meeting Discussions

OCCYSHN scheduled 4 CaCoon Regional Meetings in Bend, Pendleton, Roseburg, and Tigard in September and October, 2014. The annual, 2-day regional meetings provide professional development opportunities for CaCoon public health nurses and nurse supervisors. A 2-hour time block was reserved on the day 2 agenda for OCCYSHN staff to share preliminary results of the needs assessment and then facilitate discussions with participants on the following topics and questions:

- **Care Coordination:** What does comprehensive care coordination for CYSHCN look like? What does care coordination for CYSHCN look like in your community? What inhibits care coordination from occurring? What facilitates care coordination? What are, or what would be, the necessary ingredients for achieving comprehensive care coordination for CYSHCN in your community?
- **Service Strengths:** Are these results consistent with your experience in your community? Why or why not? How, if at all, does your local health department or CaCoon program contribute to what is working well? What resources are needed for these things to continue to work well or get better? Are there any changes, events, or other factors coming up that would threaten these things working well in the future?
- **Service Challenges:** Are these results consistent with your experience in your community? Why or why not? Where do you see opportunities to make improvements in these challenges? What resources are needed to improve or better these challenges?

CaCoon staff also participated in a Nominal Group Technique. OCCYSHN presented staff with a list of 5 broad topics (Medical Home, Transition to Adulthood, Access to Specialized Services, Access to Mental Health Services, and Family Support), some of which had subtopics and asked them: If you had to prioritize addressing these challenges for CYSHCN and their families in your community, which would you choose? CaCoon staff were given 3 dots, which they could allocate in any way that chose (e.g., 1 dot for 3 topics, 3 dots for 1 topic).

OCCYSHN staff took notes during these discussions and conducted an inductive thematic analysis of these data. Consistent with the discussion questions, the first 2 authors sought to identify themes that focused on family needs, care coordination, and system strengths and limitations. Both analysts independently reviewed the notes to identify initial broad codes and applied those codes to the text. Analysts then reviewed each other's coding and jointly developed a final coding scheme. Once the coding scheme was identified, the second author led coding for care coordination themes and subthemes and the first author led the coding for family needs and system strengths and limitations.

OCCYSHN Stakeholder Surveys

OCCYSHN analyzed responses from 7 open-ended questions in 3 needs assessment surveys: family, medical provider, and care coordinator.⁹ Content analyses were conducted of responses for 6 of open-ended survey questions. Those questions, by stakeholder survey type (and number of responses), were:

- Family: What are the 3 things that your child or family needs most but has a hard time getting? (n=963)
- Medical Providers: What are the 3 greatest barriers you encounter in attempting to coordinate care for CYSHCN with other care providers? (n=61)
- Care Coordinator: What are the 3 most important things that help you coordinate care with health and other service providers for CYSHCN? (n=96) What are the 3 greatest challenges you experience in attempting to coordinate care for health and other services for CYSHCN? (n=97)

Analysts inductively created the coding categories when conducting the content analyses of each of these questions. The first author created an initial set of categories for each item. The second author and an analyst reviewed these categories with a subset of responses and revised or added to the initial set of categories. The first and second author and analyst discussed overlap and differences across the 3 sets of codes. Following that discussion, the analyst merged the 3 code sets into 1 coding scheme, which the second author and analyst tested with additional responses. Based on their test, the second author and analyst refined the coding scheme and used it to code all of the responses. Responses were divided evenly between each analyst. Once an analyst completed her coding, it was given to the other analyst to review; thus, 100 percent of the responses were verified by a second analyst. Analysts discussed and resolved coding discrepancies.

In addition, analysts categorized the open-ended responses to the item from the family survey, "Is there anything else about your child's health, health care needs, or this survey that you would like to share with us?" One hundred fifty-four participants provided responses to this survey item. The responses were split between the second author and analyst, who categorized the responses using the major headings of this report. The purpose of this categorization was to facilitate the authors identifying examples of family responses for use in this report and other presentations of results. Analysts did not verify each other's categorization because the purpose of the categorization was anecdotal.

⁹ A review of the responses to the open-ended question on the youth survey showed that there was only 1 substantive response, which is why the open-ended question on the youth survey was not analyzed.

Appendix B: Survey Respondents Use of Social Media

OCCYSHN asked family and youth survey respondents about their use of a variety of internet media. These results are useful for program planning purposes, but did not readily fit within the larger report structure. Therefore, OCCYSHN has included them in this report appendix.

Youth survey respondents were given a list of a variety of internet media, and were asked, “About how often do you use the following types of internet media?” The response options were “at least once per day,” “a few times per week,” “one to three times per month,” “a few times per year,” or “never.” Respondents reported utilizing YouTube (50%) and Facebook (24%) “at least once per day” or “a few times per week.” Of the activities listed, youth survey respondents most frequently reported using internet media for the following activities:

- View photos, web pages, and videos for fun (60%).
- Stay in touch with friends and family (36%).
- Learn about how to do or make something (34%).
- Communicate with my health care providers (28%).

Family survey respondents also were asked this question. Similar to the youth survey results, respondents reported utilizing Facebook (69%) and YouTube (34%) “at least once per day” or “a few times per week.” Parent survey respondents most frequently reported doing the following kinds of things when they use internet media:

- Stay in touch with friends and family (75%)
- Find out about local events (70%)
- Learn about my child’s health condition (65%)
- Read the news (64%)
- Learn about how to make or do something (63%)
- View photos, web pages, and videos for fun (62%)

Appendix C: Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) Title V Needs Assessment Stakeholder Panel Discussion Meeting Summary, December 10, 2014

Overview

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) convened a group of stakeholders to discuss Oregon's Title V Needs Assessment and to gather input. The goals for the meeting were:

- To provide input about the state's Title V priorities for Children and Youth with Special Health Care Needs (CYSHCN) over the next five years;
- To better understand the capacity of the system of services for CYSHCN;
- To describe and discuss a collaborative effort to improve Oregon's system of services for CYSHCN.

Introduction

After an introduction to the state Title V Needs Assessment process, we heard about the background and context for the inclusion of Children and Youth with Special Health Care Needs (CYSHCN). We then had a presentation about the CYSHCN needs assessment process and results to date.

Reactions to assessment

We asked participants to share what resonated from the assessment results, given their work and experience.

What unmet needs resonated?

- Transportation challenges
- Wait time for an appointment
- Need for better communication amongst providers; between providers and families
- Need for care coordination
 - Between all providers and systems, including mental health, primary care and education
- Need assistance in transition to adulthood
- Need for better provider access
- Need more services and coordination around co-occurring disorders (mental and physical health)
- Need more specialists (especially dentists)
- Disparate access to services and resources, depending on geography and type of insurance
- Need for respite care
- Need more utilization of care plans
- Need more mental health services
- Need better family support

Unmet needs not specifically highlighted in assessment

We also asked participants to share what needs they didn't hear reflected in the assessment results that they see as unmet needs.

- Families/CYSHCN need help getting qualifying diagnoses
 - Entry into system can be hard, especially in rural communities
- Need more services for parents of CYSHCN
- Better access for children and adults with developmental disabilities. When there is a language/cultural barrier, this gets more difficult.
- Need more culturally competent care
- Need better coverage for certain treatments
- Need to ensure all groups are being served, especially rural families
- Need to meet families where they are and to capture family voice
- Gap in utilization of care plans is probably more significant than reflected

Assessing the CYSHCN system

We discussed a set of questions regarding system capacity for CYSHCN, including the limitations in the system; the strengths of the system; and the impact of health care transformation and early learning innovation.

Where is there capacity in the system? What can we build on?

- Increased awareness of needs of CYSHCN, especially around care coordination
- Small number of effective developmental disability caseworkers around the state
- Some strong Community Connections Network¹⁰ teams
- Improving communication across system
- Greater availability of wrap-around services
- More Community Health Workers and culturally responsive care
- Incorporating family voice and meeting families where they are has gotten better
- Some good developments on autism (applied behavioral health analysis)
- Growing knowledge around telemedicine
- Some decent work on transition
- State is looking for more resources
- More family networks
- Health care transformation/early learning innovation work offers some promise
 - Electronic Medical Records
 - Integration of dental/oral health care into general health
 - Focus on behavioral health and physical health integration (embedded workers)
 - Primary care transformation
 - Matching needs to resources and making connections to services
 - Early learning hubs create opportunity

Limitations of the system

We also discussed the challenges in the system serving CYSHCN.

- Lack of capacity and resources
- Insufficient awareness of what services and resources are available to YSHCN and their families
- Absence of family voice. Need consistent and strategic voice of all parents.

¹⁰ Community Connections Network is a program of OCCYSHN which creates multidisciplinary community-based teams which come together around a child/youth with SHN and their family

- We are not meeting parents and families where they are
- Absence of diversity “at the table”
- Reimbursement rates vary considerably, resulting in uneven coverage
- Challenges in commercial coverage
- HIPAA presents barriers to communication across systems
- Lack of Exceptional Needs Care Coordinators (ENCCs)
- Barriers to integration
- Problems in approach to rural services
- Variance among CCOs in the services available to their members
- Inflexibility of big systems
- Need more alternative therapies and to train parents in administering
- Workforce: availability of providers
- Challenges for suburban populations
- Need delegation of some services from nurses to non-licensed personnel

Formulating recommendations for priorities (federal and state)

We heard more about the Title V process, including the limitations of what we can do around federal priorities and the greater flexibility of choosing state priorities.

Federal priorities: Medical Home/Transition to Adulthood

We discussed how, under federal guidelines, Oregon needs to choose as a focus on either Medical Home, Transition to Adulthood, or both for the CYSHCN population. Participants discussed the pros and cons of choosing one or both. Highlights from the conversation include the following:

- If medical home is fully realized and effective, transition will fit in that bucket
- We need to tease out transition because we do not want it to get lost
- Helping youth learn how to access the system is critical and that is the work around transition to adulthood
- Transition to adulthood is broader than medical care. There are significant current efforts underway that address education and employment, but not health.
- There’s momentum around transition. We should leverage it.

State priorities

Our conversation around state priorities was broad. Participants suggested a variety of areas that could be priorities:

- Access to all providers for all families -- access goes beyond insurance coverage and is critical
A variety of “sub-topics” fell under access:
 - Transportation challenges
 - Need more providers across Oregon, especially in rural areas
 - Need timely access to providers
 - Lack of equity in coverage/Reimbursement challenges – differences in covered services and reimbursement rates between private insurance and OHP and across CCOs around the state (what might be covered under one CCO may not be covered under another CCO).
 - Assistance in navigation of the system

- Need for better cultural competence and responsiveness
- Disparities in access across groups (racial, geographic, socio-economic)
- Need more access to specialized services, broadly
- Access to providers when child has co-occurring diagnosis and treatment
- Medical home – specific focus on CYSHCN; can encompass all; maybe at a tipping point)
- Mental health – utilization driver; least accessible service; feels urgent; can lead to happy, healthy employable life
 - Includes education of providers, integration, diagnosis and treatment
- Care Coordination
 - Includes communication among providers and families, care plans
 - Possibility to create efficiency and improve quality in the system
- Transition to adulthood – all transition, including medical transition; need to start early

After listing priorities, we used dots to gauge interest in different areas for focus. There was significant interest in addressing lack of reimbursement; looking at disparities in access; and focusing on mental health as well as care coordination.

Next steps and SOS grant

We shared next steps with participants and described a federal grant procured by OCCYSHN around creating a system of services for CYSHCN. We asked participants about their interest in participating in some way in the initiative and many indicated a willingness to learn more and be involved. We will share information with the group moving forward and let them know about opportunities for participation and partnership.