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

Nearly one in five Oregon children has a special health care need.[1]

Children and youth with special health care needs (CYSHCN) either have chronic health conditions, or they are at risk for having them. The conditions can be physical, developmental, behavioral, or emotional. CYSHCN need more health and related services than other children.

There are many conditions that might qualify as a special health need. A few examples are asthma, autism, deafness, cerebral palsy, depression, diabetes, and muscular dystrophy.

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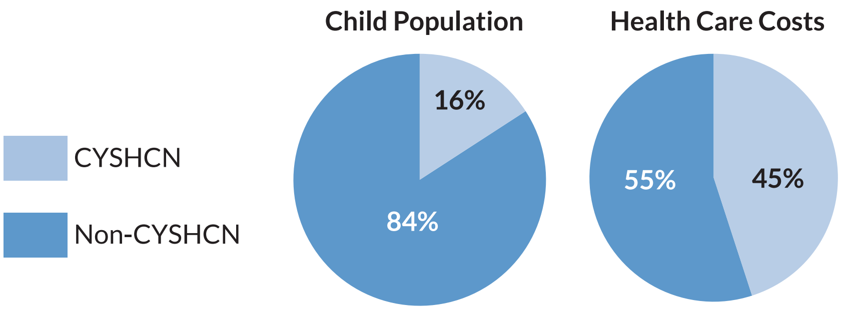
Special health care needs can affect any child. Nationally, children and youth with special health care needs (CYSHCN) do not enjoy the same levels of health care, education, family health, and healthy lifestyles as other children.[2] Caring for CYSHCN affects families, schools, communities, and Oregon as a whole. This overview describes some challenges faced by Oregon CYSHCN and their families.

Caring for CYSHCN is expensive. Nationally, CYSHCN make up 16.2% of the child population, yet they account for 45% of the total health care costs for children (excluding dental care, long term care, education services, and institutional care costs).



Newacheck, P.W., & Kim, S.E. (2005). A national profile of health care utilization and expenditures for children with special health care needs. Archives of Pediatric and Adolescent Medicine, 159, 10-17.

Even though most Oregon CYSHCN have health insurance, 21% of their families reported having problems paying for their child's medical bills. Their out-of-pocket expenses averaged twice those of other families.[1]

Healthcare can be hard to access. Most medical specialists in Oregon are located in cities or large towns. Families living outside those areas can not always get the care their CYSHCN need close to home. Public health nurses reported to OCCYSHN that dental care, mental health services, primary care, and specialty care are harder to access for CYSHCN in rural Oregon communities. Families who are able to travel to distant specialty care providers face additional expenses such as transportation, lodging, and child care for their other children.

Youth with special health care needs need support to transition to adult health care. While over 90% of American CYSHCN live to adulthood, they are less likely than non-CYSHCN to finish high school, attend college, or be employed.[3] Health and health care are two of the key challenges to moving into a successful adulthood.[4]

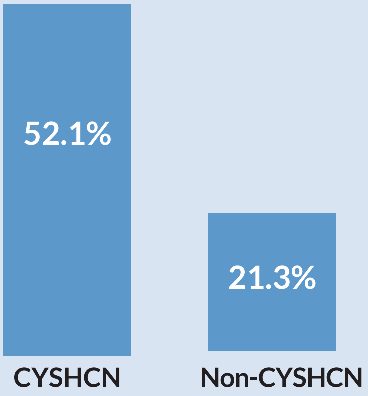
There are standards for transition services in medical practices. Those standards include helping patients make a plan for getting appropriate adult health care, and tracking progress on that plan.[5] 65% of youth with special health care needs did not receive the services necessary to transition to adult healthcare in 2009/10.[3]

CYSHCN come from diverse families and cultures. Thirty-two percent of Oregon CYSHCN are identified by their families as being non-Caucasian.[1] To be effective for everyone, services for CYSHCN must be sensitive to differences in culture, language, and literacy. Even English speakers sometimes have trouble understanding health care and insurance terminology.

CYSHCN need their care coordinated. Most CYSHCN require a variety of professionals to address their care and services. Forty-nine percent of CYSHCN in Oregon have two or more chronic health conditions,[1] which increases the number of people involved in their care. Getting the right information into the right hands at the right time is not easy when there are different programs, schools, agencies, and health care providers involved.

Families of CYSHCN don't always have the tools they need to coordinate their children's care. Parents of Oregon CYSHCN were three times as likely as other parents to report that they could have used extra help coordinating their child's care.[1]

Percentage of Oregon Children with Two or More Adverse Childhood Experiences (ACEs)



Oregon CYSHCN are twice as likely to have two or more Adverse Childhood Experiences (ACEs) than non-CYSHCN.[1] ACEs (including violence, substance abuse, divorce, and deprivation) increase the risk for additional health and social challenges.[6]

The full report of the 2015 Needs Assessment findings from the Oregon Center for Children and Youth with Special Health Needs is available online at www.occyshn.org|publications. This publication is available in alternate formats.

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[1] National Survey of Children's Health. (2011-2012). Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12-20-2015 from www.childhealthdata.org.

[2] U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2011). Children with special health care needs in context: a portrait of states and the nation 2007. Rockville, Maryland: U.S. Department of Health and Human Services.

[3] National Survey of Children with Special Health Care Needs. (2009-2010). Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12-20-2015 from www.childhealthdata.org.

[4] U.S. Department of Health & Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (2015) "Title V maternal and child health services block grant to state program. Guidance and forms for the Title V application/annual report. Rockville, MD: Author.

[5] VanLandeghem, K., Sloyer, P., Gabor, V., & Helms, V. (2014). Standards for systems of care for children and youth with special health care needs. A product of the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs project. Washington, DC: Association of Maternal & Child Health Programs

[6] Felitti, V. J., & Anda, R. F. (2009). The Relationship of Adverse Childhood Experiences to Adult Medical Disease, Psychiatric Disorders, and Sexual Behavior: Implications for Healthcare. In R. Lanius, E. Vermetten, & C. Pain (Eds.), The Hidden Epidemic: The Impact of Early Life Trauma on Health and Disease (pp. 77-87). Cambridge University Press.

Access to Care for Oregon's Children and Youth with Special Health Needs

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Children and youth with special health care needs (CYSHCN) require more and different services and supports than other children. Getting these services and supports can be challenging. Nearly one third of Oregon families report that their CYSHCN have unmet service or equipment needs.[1]

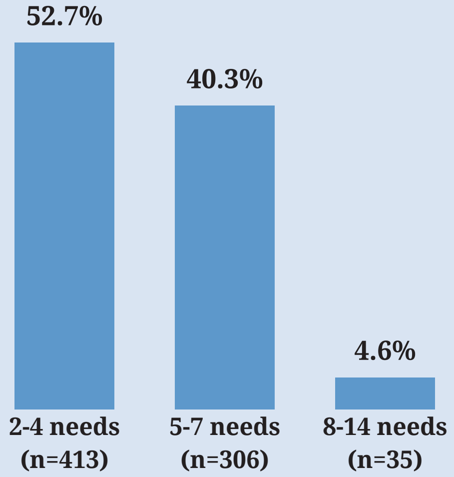
Insurance. Most Oregon CYSHCN have health insurance.[2] However, health and service providers across the state reported to OCCYSHN that insurance does not always cover the services CYSHCN need. They reported that private insurance plans don't provide adequate coverage for mental health services for CYSHCN, and that it does not cover the cost of transportation.

For people insured by Medicaid, the Oregon Health Plan (OHP) is implemented by Coordinated Care Organizations (CCOs). Providers reported to OCCYSHN that coverage varies by CCO. Examples they cited of services and supports which may or may not be covered included: mobility aids (like wheelchairs), genetic testing, and mental health care.

Health and service providers also reported that OHP does not always cover the cost of care received across state lines, which is sometimes the closest care available for families living near Oregon's borders. While health care providers could consult with families remotely using phone or video technology, insurance will not reimburse them for that time, which makes them less likely to use those resources to serve rural CYSHCN.

Another challenge reported is that some health care providers don't accept OHP. Since there are already relatively few doctors and dentists practicing in rural and semi-rural Oregon, the fact that some of them don't accept OHP can result in a months-long wait for an appointment.

Percent of Families of Oregon CYSHCN with Numbers of Specific Health Care Service or Equipment Needs in the Past Twelve Months



Data source: National Survey of Children with Special Health Needs, 2009/2010. The survey asked about the following needs: 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.

Information & Communication. Some families have trouble getting their CYSHCN's needs met because they aren't sure what care is needed, or where to look for services in their area. There are sometimes language, literacy, or cultural barriers to getting care for CYSHCN. Also, qualifying for services can be difficult for children with health conditions that don't fit neatly into one system of services (like mental illness and developmental disabilities).

Geography & Transportation. Oregon is a large state (nearly 100,000 square miles). The specialized care and services CYSHCN need are easier to find in the cities and large towns of the Willamette Valley than in the rest of the state. Families living in rural Oregon might have to travel some distance to get care, which takes time and money. OHP offers help with transportation costs in some cases, but families and providers report that the service can be unreliable and hard to arrange. Transportation costs are not typically covered for children with private insurance.

Twenty percent of families of Oregon CYSHCN report that paying for transportation to get their child to health care providers is "always" or "usually" hard. In addition to gas costs, they may face lodging costs, and childcare costs for siblings. Rural health care providers report that families who live far from specialty care and services sometimes end up relying on the emergency room for their children's care.

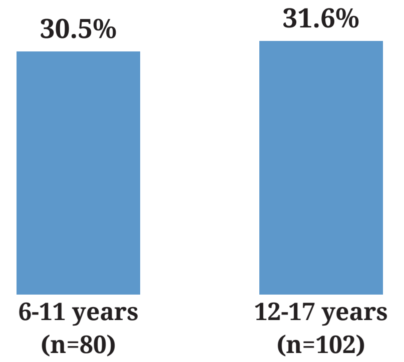
Mental/Behavioral Health. Nationally, the most commonly reported unmet need for CYSHCN is mental health care or counseling.[3] A 2009 study found that 38% of families of CYSHCN enrolled in Medicaid had a child with a mental health problem in need of treatment.[4] Of CYSHCN who needed mental health care in Oregon at that time, 7.5% did not get the care they needed.[1]

A quarter of the families responding to OCCYSHN's 2015 Needs Assessment survey said that mental or behavioral health services were one of the top three services they had difficulty getting for their child. There are various reasons this care might be hard to get. Sometimes insurance did not cover the services. Sometimes insurance coverage is limited to just a few sessions, when more are needed. Additionally, health care providers and care coordinators reported that many areas of the state don't have enough mental health providers to meet the demand.

Care and services that families of CYSHCN report are hard to get:

- Allied health care (physical therapy, occupational therapy, speech/language therapy)
- Behavioral and mental health services (including autism-specific therapies)
- Health supports (e.g., durable medical equipment, mobility aids, home health care, palliative care)
- Respite care
- Specialty dental care
- Specialty medical care

Percent of Oregon CYSHCN (age 6-17 years) needing mental health care in the past twelve months.



Data source: National Survey of Children with Special Health Needs, 2009/2010

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[1] National Survey of Children with Special Health Care Needs. (2009-2010). Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 12-20-2015 from www.childhealthdata.org.

[2] National Survey of Children's Health, NSCH 2011/2012. Data query from the Child and Adolescent Health Measurement Initiative. Data retrieved 12/23/2015 from www.childhealth.org

[3] 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.

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Children and Youth with Special Health Care Needs: Responding to Differences in Culture & Language

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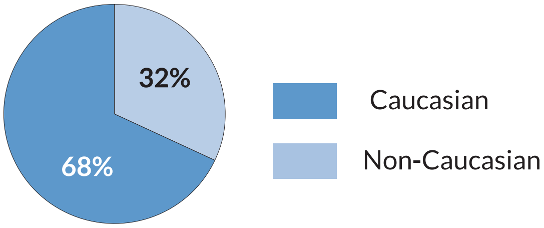
Culture refers to more than coming from another country or speaking another language. It also includes education, ethnicity, income level, race, and religion. These factors can affect how people talk about health, and how they find and use health care.

Oregon's demographics are changing. Minority ethnic and racial populations (especially Latino) are growing faster than the national average.[1] This increasing diversity calls for a focus on providing "culturally and linguistically appropriate services" (CLAS) for children and youth with special health care needs (CYSHCN). When health care is offered in a way that is sensitive to family culture, children get better care.[2]

Racial Distribution of Oregon's Children and Youth with Special Health Care Needs



Data Source: National Survey of Children's Health, 2011/2012

A 2002 study by the Institute of Medicine found that minorities with the same health insurance and similar access to healthcare as non-minorities received a lower quality of care than Caucasians.[2]

The national Office of Minority Health developed standards for working effectively in cross-cultural situations. The goal is to

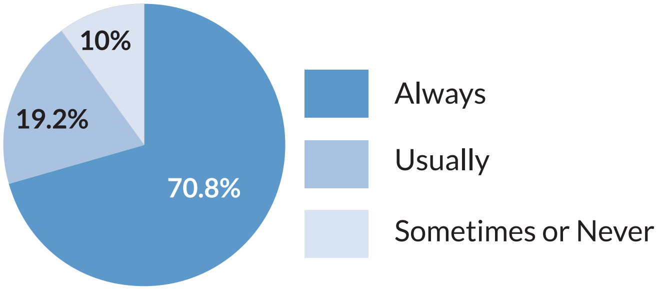
> *"provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs."*[3]

Education, income, and language differences affect the health care experience.

- 18.9% of Oregon families with children under age 18 live in poverty.[4]
- One in ten Oregon residents did not graduate from high school.[4]
- 6.1% of Oregon's population speaks English "less than very well."[4]
- One in ten Oregon residents is foreign-born. Of those foreign-born residents, 49.2% speak English "less than very well."[4]
- In 2011/12, Spanish was the primary language spoken in the homes of 4.7% of Oregon's CYSHCN.[5]

People who work with CYSHCN around the state reported to OCCYSHN that there are not enough CLAS available. They reported communication problems for families from African, Asian, and Slavic countries, and for Spanish-speaking families. They also pointed to the need for more culturally and linguistically appropriate services for Oregon's migrant farm workers, who come from a variety of cultures and who speak various languages.

Oregon families of CYSHCN who reported that their child's health care providers were sensitive to their family's values and customs



Data Source: National Survey of Children's Health, 2011/2012

In partnership with the Oregon Health Authority's Maternal and Child Health Division, OCCYSHN has declared it a 2016-2021 statewide priority to increase the availability of culturally and linguistically appropriate services for CYSHCN.

Communicating about Health Care: *Examples of Cultural and Linguistic Challenges*

- Not every culture shares the same beliefs about illness and health.
- Families with limited English might have trouble informing doctors about their child. They also might find it difficult to understand medical advice given in English.
- Some cultures consider it disrespectful to question a doctor's opinion. Parents might not share doubts or ask important questions about their child's diagnosis or treatment.
- Medical terms are often unfamiliar and confusing, even for English-speaking families.
- Written instructions assume that people can read, which is not always the case.
- Health care providers may not be aware when health care creates financial hardship for families (because of missed work, travel, childcare, medical bills, etc.).
- Missed appointments or failure to follow instructions can interfere with the relationship between families and health care providers.

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[1] Oregon Department of Administrative Services, Office of Economic Analysis. (2011). Oregon's demographic trends. Retrieved on April 24, 2014, from http://www.oregon.gov/DAS/OEA/docs/demographic/or_pop_trend2011.pdf.

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[4] United States Census Bureau. (2014). American Fact Finder: American Community Survey (ACS). Retrieved February 10, 2016, from http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=CF

[5] National Survey of Children's Health, NSCH 2011/2012. Data query from the Child and Adolescent Health Measurement Initiative. Data retrieved 12/23/2015 from www.childhealth.org.

Medical Home and Care Coordination for Oregon Children and Youth with Special Health Care Needs

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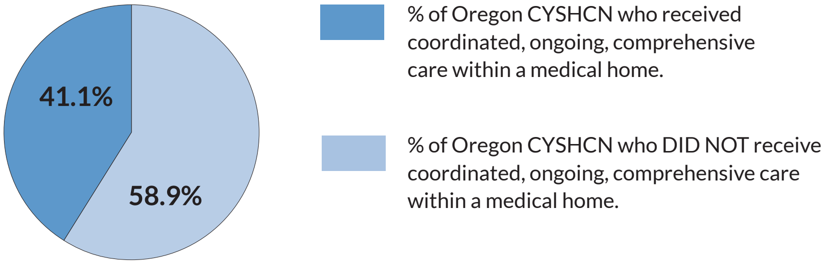
Children and youth with special health care needs (CYSHCN) require more care and services than other children. It is important that CYSHCN's care and services be coordinated, because their care can be especially complicated and costly.

CYSHCN who have a medical home are more likely to get the care they need. (See blue box for a description of medical home.) A lack of medical home is associated with more out-of-pocket costs for families, and fewer referrals to needed specialty care.[1]



Data Source: National Survey of Children with Special Health Care Needs, 2009/2010

Family-centered and easily-accessible care are core components of a medical home. Oregon families of CYSHCN report difficulty finding care that meets those standards. In 2011/12, 37% of Oregon CYSHCN received care that was not family-centered.[2] More than half the parents who responded to OCCYSHN's 2015 Needs Assessment survey said they had trouble getting quick and convenient appointments for their CYSHCN. They also reported long waits in the waiting room before appointments, which can be especially challenging for some CYSHCN and their families.

The Oregon Health Authority's Patient-Centered Primary Care Home (PCPCH) program sets standards that medical practices must meet to qualify as a medical home. Most of the PCPCHs in Oregon are located along the I-5 corridor between Portland and Eugene. Oregon CYSHCN who live elsewhere in the state are less likely to have access to a PCPCH.

What is a medical home?

Medical home is a way to offer primary healthcare. It is "a partnership between the patient, family, and primary provider in cooperation wtih specialists and support from the community."[3]

Medical homes offer care coordination and planning, easy access to advice and appointments, and a respectful environment where families of CYSHCN are included in decision-making. Care provided in medical homes is sensitive to the culture and language of patients and their families.[4]

It is especially important for CYSHCN to be served by a medical home. Their care extends beyond their family and the primary care clinic. They might require specialized doctors, speech or occupational therapies, mental health services. etc. Schools or social service agencies are often involved in addressing the child's needs.

A medical home provides a place to coordinate care, and to improve communication between all the people involved.

Medical home is recommended for children by the American Academy of Pediatrics and by the Affordable Care Act.

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There is a pressing need for better care coordination for Oregon CYSHCN. ***Forty-seven percent of families surveyed by OCCYSHN reported "rarely" or "never" getting as much help as they want coordinating their child's care.*** Thirty-four percent of Oregon CYSHCN did not receive one or more of the elements of effective care coordination:

- communication between doctors when needed
- communication between doctors and schools when needed
- families getting needed help coordinating care[2]

OCCYSHN's 2015 Needs Assessment identified communication issues as a barrier to effective care coordination. Communication problems were reported amongst professionals, and also between professionals and the family members of CYSHCN.

One way to support good communication and effective care coordination is to use a shared care plan. A shared care plan provides a central place to record information about a child's needs, and what is being done to address those needs. The plans help identify who will do what, and when. They allow families and providers to clarify goals and timelines together. When care plans are shared, the people and programs serving CYSHCN are more likely to work effectively together.[5]

Fewer than one third of parents surveyed by OCCYSHN reported that their child had a care plan. Of those, only half reported that the care plan had been shared with all the child's health care providers.

Shared care planning requires time and effort. Professionals and families must develop a process for creating, updating, and sharing the plans. While it is challenging, shared care planning offers the promise of improved communication and coordination on behalf of CYSHCN.

What is care coordination?

Care coordination is a central part of a medical home. Care is coordinated when a CYSHCN's family and the child's health and service providers communicate and work together effectively to meet the child's needs. Care Coordinators find resources for families, make referrals, and track progress on care plans. They help ensure good communication between CYSHCN, their families, health care providers, and community service providers.

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Oregon's Youth with Special Health Care Needs: Transitioning to Adult Health Care

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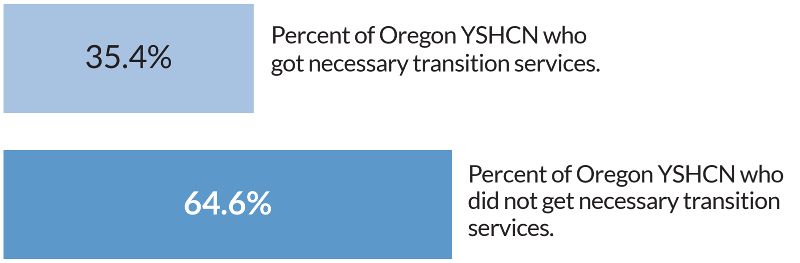
Moving from pediatric to adult health care can be a challenge for any young person. That transition may be especially complicated for youth with special health care needs (YSHCN). YSHCN usually need to find new health care providers who can treat their conditions. They might also need to navigate financial or legal changes. Most youth (age 18-23) in one study were unprepared to manage their own health care.[1]

YSHCN usually grow up to become adults with special health care needs. Over 90% of YSHCN live to adulthood, but they are less likely than others their age to complete high school, attend college, or be employed.[2] Health and health care are two key challenges to a successful transition to adulthood.[3] Because YSHCN are likely to become adults with chronic conditions, preparing for their adult health care can help contain costs and improve quality of life. [4]

The transition to adult healthcare is more successful when it is planned in advance,[5] but that planning does not always happen. National data show that most Oregon YSHCN (age 12-17) do not get the help they need transitioning to adult healthcare.



Data Source: National Survey of Children with Special Health Needs 2009/2010

Fewer than half of the health care providers who responded to OCCYSHN's 2015 Needs Assessment survey reported that they help teen patients prepare for adult health care. YSHCN confirmed those numbers in their responses. Only 12% of YSHCN said their doctor

To manage their own health care, young adults need the skills to:

- Find adult health care providers who can meet their needs
- Make and keep medical appointments
- Manage medications
- Make best use of their health insurance and other financial resources (e.g. Supplemental Security Income)

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talked with them about finding a new healthcare provider when they turn 18.

As part of the 2015 Needs Assessment, OCCYSHN held a panel discussion with families and professionals who serve YSHCN. Transitioning to adult health care was one of the discussion topics. The panelists said that while there are educational and vocational resources for Oregon YSHCN, there is less focus on their health care. Health problems can interfere with work or school, making it especially important for YSHCN to plan for their future care.

The panel concluded that Oregon health care providers need more guidance. Helping teen and young adult patients prepare for adult health care is not a regular part of medical training. Pediatric health care providers might not know how best to help. The panel recommended increased training for professionals on how to support patients as they transition to adult health care.

Panelists also noted that more support is needed for those families of YSHCN who might never be able to manage their own care, because their health conditions make it impossible. In addition to finding adult health care providers for their YSHCN, these families need to have legal and financial matters organized so that they can continue to manage their child's care into adulthood.

Health care providers can help youth with special health care needs transition to adult health care in the following ways:[6]

- Create and follow standard procedures in their practices to help YSHCN prepare for adult health care.
- Keep track of the YSHCN patients who are ready to transition to an adult care provider, and which patients have already done so.
- Discuss with YSHCN and their families what help they need to transition to adult health care.
- Work with each youth and family to make a plan that fits with the family's culture.
- Communicate the transition plan to the youth's adult health care provider.
- Be available to consult with new adult health care providers about the patient.
- Follow up with YSHCN 3-6 months after transferring care to see how things are going.

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