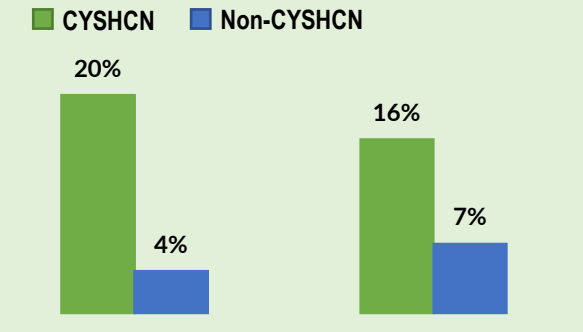
Supporting Economic Stability for Families of Children with Special Health Care Needs *2022*

Children and youth with special health care needs (CYSHCN) require more health care services than other children. As a result, their families spend more than others on medical bills and related expenses like child care, transportation to appointments,[1] or housing that can accommodate their child's needs.

These additional costs can result in financial difficulties. In 2019-2020, 22% of CYSHCN lived in families with annual incomes below 100% of the federal poverty level, as compared to 18% of non-CYSHCN.[2] Families of CYSHCN are twice as likely as other families to have problems paying their child's medical bills.[3,4]

In addition, family members of CYSHCN, including those in Oregon, face potential impacts on their employment. Some have to miss work, or even forgo employment altogether to care for their children (see Figure 1). One parent of a medically complex youth (Parent A) reported that for years their spouse could not work because they had to care for their young adult. Currently, their spouse can only work half time from home, which significantly reduces their family's income in the short-term. Additionally, this parent explained that their spouse's social security income will be negatively affected by years of lost wages, thus reducing their long-term retirement income.

Figure 1. Oregon families of CYSHCN experience greater financial challenges than families without CYSHCN



Data source: *National Survey of Children's Health 2019-2020*

The expenses associated with having CYSHCN with very complicated health conditions affect every aspect of family life. Three parents described their families' experiences for this brief, to contextualize quantitative survey results. Decisions about families' geographic locations, homes, vehicles, and jobs were governed by their children's complex needs. These decisions had significant financial ramifications. For example, one family reported spending all their savings on a vehicle that could accommodate a wheelchair.

A recent study estimated the average lost earnings from forgone family employment due to a child's special health care needs at approximately $18,000 per year.[5] In addition to reduced household income, missing work or forgoing employment results in missed professional opportunities.[2,6] For example, a second parent of a medically complex youth (Parent B) said *"I had to let go of my dream job because insurance at the new job was not adequate for [my child]'s health care needs."* Both Parents A and B reported that they can only take jobs that provide health insurance for their children. Although even with insurance, health care costs affect their family finances.

Parent B reported that their child has private insurance and Medicaid, but the family still pays $400 each month in co-pays for specialty medications. Parents A and B both reported finding workarounds to secure necessities for their child that insurance does not cover. For example, Parent B reported using thrift stores to buy lower-cost adult-sized diapers for their growing youth. They asked thrift store staff to contact them when the correct size is donated by the Veterans' Administration or local nursing homes.

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Care Coordination and Financial Well-Being

Receipt of effective care coordination is a standard of care for CYSHCN; that is, all CYSHCN should "*have access to patient- and-family-centered care coordination that integrates physical, oral, mental health and community-based services.*"[7] Coordinating care for their children is one of many caregiving responsibilities that families of CYSHCN have. When care is not coordinated by professionals, family members must do their best to ensure that their child's multiple care and service providers have accurate and timely information, and that the providers' decisions align. Only 35% of families of CYSHCN in Oregon reported that they got effective care coordination when they needed it.[1,8]

Parents A, B, and C all reported that they didn't get help coordinating their child's care. They coordinate care on their own, while juggling work and caring for their family. Parent B described coordinating eight providers to get their child's bloodwork done. Parent A described needing to contact their child's pediatrician and all their specialists to coordinate lab work every time the child's feeding tube is changed.

> *"My daughter has seven different health care providers. I pretty much coordinate them all. Caring for my daughter, and organizing her care, is a full-time job. I spend about 30 - 40 hours a week on it. In reality I couldn't work."*
>
> – Parent C

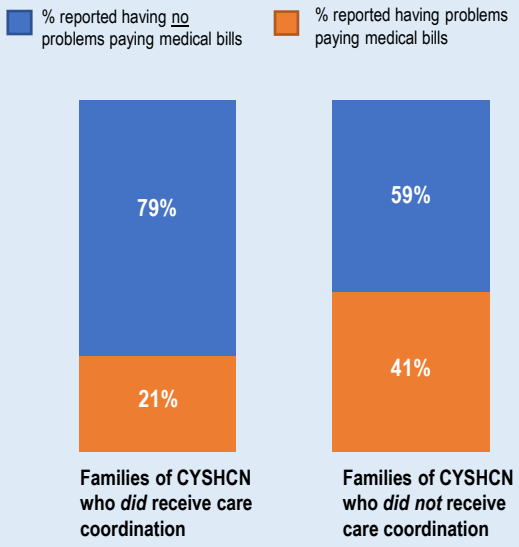
Serving as a care coordinator takes significant time and has financial implications, like lost income. Parents A and B said that access to professional care coordinators for their CYSHCN would free up their time to focus on family and work.

Parents of CYSHCN who received care coordination reported missing less work than parents who did not.[9] Additionally, our analysis of National Survey of Children's Health data showed that families of CYSHCN who received needed care coordination were significantly less likely to report problems paying their child's medical bills, compared to those who did not (Figure 2).[3,10]

> *"Whenever my child needs a feeding tube change, I have to contact my child's pediatrician and every single specialist to ask who needs labs. They message me back about what labs to get. It is time-consuming. Why isn't there someone who automatically says 'This child needs lab work done.'? All of these things take time away from my kids, family members, and work."* – Parent A

In 2020, Oregon's Governor directed Oregon's Coordinated Care Organizations, which administer Medicaid to more than one-third of Oregon CYSHCN,[3] to include a focus on social determinants of health and health equity.[11,12] A major emphasis of this work is on economic stability and financial well-being, which is associated with improved overall health.[13,14] Care coordination may be an effective strategy for addressing the disparate health care cost burden faced by the families of Oregon's estimated 179,228 CYSHCN.[2]

Figure 2. Nationwide, families of CYSHCN who did not receive care coordination were more likely to report problems paying their child's medical bills than families who received care coordination



Data source: OCCYSHN analysis of National Survey of Children's Health 2016-2017 data

Citations

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[8] In the National Survey of Children's Health, the Child and Adolescent Health Measurement Initiative (2021) defines effective care coordination as satisfaction with communication between doctors when needed, satisfaction with communication between doctors and schools when needed, and getting needed help coordinating care.
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[10] National findings are included in the brief because Oregon data on CYSHCN is limited in sample size and meaningful findings on financial hardship cannot be obtained.
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