

# social determinants of health

## CONNECTING THE DOTS



MARCH 2021

This month, we are highlighting Children and Youth with Special Health Care Needs (CYSHCN), a population defined by the federal Maternal and Child Health Bureau as “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.”

According to the [National Survey of Child Health](#), 18.8% of Colorado’s children ages 0 to 17 have a special health care need, which is approximately 341,000 children. To put this into perspective, we would need to fill every seat of a football stadium almost **five times over** to reach this number. A large body of evidence illuminates disparities experienced by this population, which are worsened by our complex and fragmented health care system.



As a parent of an adult child with special health care needs, I will always remember the day my daughter’s health care provider sat me down for what ended up being a very difficult conversation. Two long years of tests, hospitalizations, therapies, medications, insurance battles and sleepless nights still had not prepared me for the challenge of the moment. The diagnosis at the time: ‘profound mental retardation’ (which we now call profound intellectual disability), epilepsy, failure to thrive, bilateral hearing loss. The unknowns. The fear. The health care system became the new hallways of my life, complete with extraordinary relationships with an intricate roster of over 40 health care providers over 30-plus years. In partnership with countless physicians, nurses, administrators, and nonprofits, many of which were founded by parents, I have spent decades dedicated to building an equitable health care system to support CYSHCN. Through this article, I hope to share some of the concerns still facing CYSHCN and how you can become more engaged in supporting this unique population.

-Eileen Forlenza, practice facilitator, Colorado Access



If you would like to learn more about how Eileen’s daughter’s primary care provider served as their medical home, email Eileen at [eileen.forlenza@coaccess.com](mailto:eileen.forlenza@coaccess.com).

*This new Colorado Access series will illuminate social factors that lead to health inequalities and disparities, or help to decrease them. We hope this monthly series will support your existing efforts by providing resources and educational opportunities while exploring current trends and best practices.*

*We know there are timely and progressive efforts in place to address the health disparities experienced by so many, sometimes by providers or community partners within our own network. We will share information about these efforts in the hope that it might lead you to consider what might be realized in your own practice or organization.*

*Each month we will introduce a topic and offer some brief highlights. If you want to dive a bit deeper, we will also include links to articles or websites that provide more comprehensive information.*

The federal definition of CYSHCN is broad and encompasses a wide range of diagnoses. The most common diagnoses affiliated with CYSHCN in Colorado are ADD/ADHD, asthma, behavioral disorder, anxiety/depression, learning disability, developmental delay, speech disorder, autism, genetic disorder, brain injury, intellectual disability, epilepsy and diabetes. Click [here](#) to read more.

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Unfortunately, **only 46.2%** of CYSHCN in Colorado have a primary care medical home. Without this support, these children are receiving their primary care through less-effective means, such as emergency department visits or specialists. As a member of our provider network, you can receive additional training and support to equip your team to include and serve this unique population. For more information, please email [practice\\_support@coaccess.com](mailto:practice_support@coaccess.com).

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Since 1935, the federal government has required that every state monitor and subsequently support CYSHCN. In Colorado, the state agency designated for this role is the [Health Care Program for Children with Special Needs](#) (HCP), which is part of the Colorado Department of Public Health and Environment (CDPHE). Our care management team works with the state and local HCP teams to assure care coordination services are provided to CYSHCN. This benefit is available to all providers in our network. In addition, there are a myriad of community-based organizations that provide guidance and much needed parent-to-parent support. [Here](#) is a list you can offer to parents to help them find the right resources.

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Children and youth with special health care needs are the most rewarding patients I see. Their parents are inspiring and as children become young adults you know that you've really contributed to improving someone's life. They will also make you a better person, a better doctor and renew your enthusiasm for patient care.

—Dr. Laura Pickler, Chief of Family Medicine, Children's Hospital Colorado



There are several community-based organizations dedicated to supporting providers as well as families with children with special health care needs. Here are a few of our recommendations:

- [Family Voices of Colorado](#) provides advocacy and guidance for families who have children with complex medical needs. This organization specializes in helping providers and families navigate through the complexities of Medicaid waivers.
- [Parent to Parent of Colorado](#) connects families with other families across Colorado to share lessons learned while providing informational and emotional support. Parent to Parent is a program of [Ability Connection Colorado](#).
- [Got Transition](#) supports youth with special health care needs to transition from their pediatric to adult health care. This national organization works with providers and patients to assure continuity of care through this critical transition.



*Photo provided courtesy of Parent to Parent of Colorado*



If you know of creative approaches or partnerships that are addressing health disparities, either by your organization or another entity, please contact us at [practice\\_support@coaccess.com](mailto:practice_support@coaccess.com).

**We would love to share this information!**