

Who are Children with Special Health Care Needs??

Children and youth with special health care needs (CYSHCN) have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition. They usually require health and related services of a type or amount beyond that required by children generally. In fact, children with special health care needs (ages 17 and under) account for 40% or more of medical expenditures for children overall.*

A Personal Look at a Family in Colorado:

Seven-year-old Jake has Angelman Syndrome, a genetic disorder involving significant developmental delay, seizures, movement and balance problems and behavioral issues. Though Jake has been covered by both parents' private insurance plans, out-of-pocket expenses for co-pays, therapies, and equipment not covered by insurance ranged from **\$1,000-\$1,500 each month**. Jake's family struggled to make ends meet given the high cost of his care.

Fortunately, with the assistance of Family Voices, Jake was able to enroll in Colorado's new Medicaid Buy-In Program for Children with Disabilities. He is now able to access many new services, including speech therapy, physical therapy, a new communication device, and orthotics, allowing him to make significantly more progress toward his health and developmental goals, without his parents facing crippling out-of-pocket costs. Today, Jake's mom is highly active with Family Voices and is working with the state's Medicaid agency to identify and resolve challenges within the system.



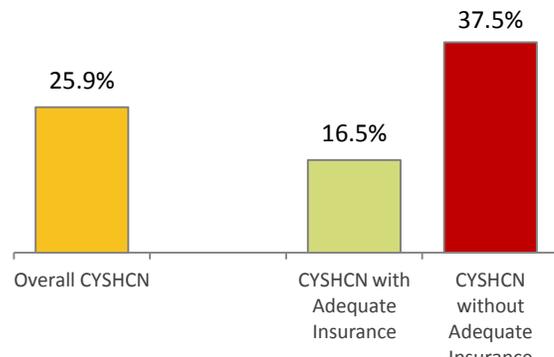
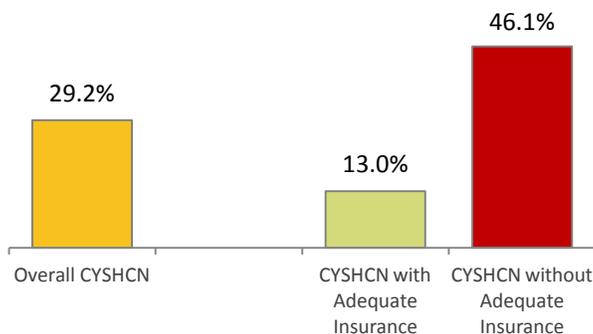
By the Numbers*: CYSHCN in Colorado:

	%	Total #
Prevalence of Children & Youth with Special Health Care Needs (CYSHCN), among all children age 0-17	13.7%	167,524
	% of CYSHCN	# of CYSHCN
Currently insured CYSHCN whose insurance is inadequate	44.8%	70,432
Impact on the Family:		
CYSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year per child	30.3%	50,409
CYSHCN whose conditions cause financial problems for the family	29.2%	48,544
CYSHCN whose families spend 11 or more hours per week providing or coordinating health care	11.0%	17,804
CYSHCN whose conditions cause family members to cut back or stop working	25.9%	43,185

Financial Impact*: Families of CYSHCN Reporting that Their Children's Conditions Cause:

Financial Problems for the Family

Family Members to Cut Back or Stop Working



*National Survey of Children with Special Health Care Needs. NS-CYSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 03/14/2013 from www.childhealthdata.org.

Family Voices Colorado (FVC): The Family-to-Family Health Information Center in Colorado

An Overview of Our Work:

The mission of Family Voices Colorado is to improve access to and quality of health care for children and youth with special health care needs. Family Voices Colorado:

- helps families of CYSHCN become full partners in health care decision-making to get the care they need;
- trains health care providers and other professionals to understand the medical home approach; and
- identifies areas where family leadership can improve policy discussions and decisions.

Trained Family Navigators help implement the goals of Colorado F2F to educate and support families and professionals within their communities. Information, training, and resources provided will be assessed for cultural competence, and satisfaction surveys will evaluate the usefulness of F2F services.

By The Numbers

From June 2011 through May 2012 FVC reported:

	Families	Professionals
Total People Served	10,400	3,591
People Assisted and Trained	6,575	3,316
People Reached by Newsletter	825	275
Materials Disseminated	12,836	

As a result of assistance/training provided by FVCO:

% Families Reporting Better Able to Partner in Decision-Making	98.5%
% Families Reporting Better Able to Find and/or Learn about Community Services	98.6%
% Families Reporting More Confidence in Getting Health Care and Services Needed by Child	95.5%

Activity Highlight: Fast Fact Series

Families often call multiple agencies (or the same agency multiple times) when an initial referral turns out not to be well suited to a family's need. To address this problem FVC developed a series of "Fast Fact" publications, which have proven to be an efficient and effective way to inform and empower families to locate the health or disability related community resources they need.

To date, FVC has developed Fast Facts on the following topics:

- Medicaid
- SSI & Waivers
- Medical Appointments for Spanish-Speaking Families
- Transition from Pediatric to Adult Health Care
- Colorado-Specific Resources
- School Accommodations and Modifications
- Camp Resources
- Animal-Assisted Therapies

Feedback has been very positive; families report that they have passed on the Fast Facts to their listservs, support groups, and other community connections where they encounter other families of CYSHCN.

Top 10 topic areas provided during 1-1 Assistance and Trainings (all F2F HICs):

- Public Health Care Financing (Medicaid, SCHIP, etc)
- Family Support
- Communicating w/ Child's providers
- Disability Awareness
- Providing info to increase skills/knowledge
- Care Coordination
- Advancing Cultural Competence
- Education/Schools
- School-based Health Care
- Mentoring

From the Director:

Family Voices Colorado continues to play a key role in the Medical Home Project in Colorado, having certified 267 clinics/practices to become Medical Home Providers in the last 12 months. As part of the certification process, FVC staff conducted surveys of 3,738 medical staff providers and 4,806 families from those practices.

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