

# Children with Special Health Care Needs in Nevada

## Who are Children/Youth with Special Health Care Needs?

Children/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 Nevada:

*“My son was diagnosed with autism as a child, but did not receive the treatment he needed because my health insurance did not cover it and I didn’t know where to go to look for help. When I contacted Family TIES, it changed my life. I have received a lot of support and information to help me with my son’s transition services, guardianship, employment opportunities, and reviewing the different health care financing options. When Family TIES connected me with another family that has a child with autism, it was a great relief. The support I received from this family was very important because they shared their experiences, their successes, and failures. I am very grateful and I thank Family TIES for helping us.”*

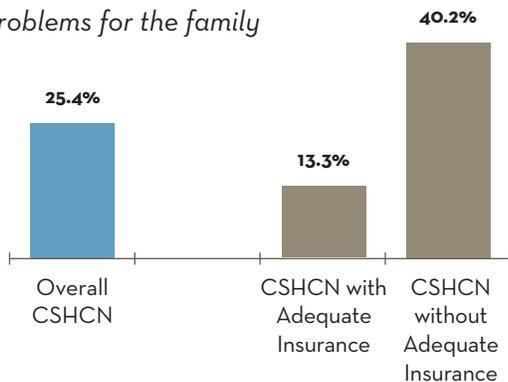


## By the Numbers: CSHCN in Nevada:

Prevalence of Children with Special Health Care Needs (CSHCN), among all children age 0-17	12.0%	82,108
	% of CSHCN	# of CSHCN
Currently insured CSHCN whose insurance is inadequate	38.1	28,055
<b>Impact of CSHCN on the Family:</b>		
CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year per child	26.5	21,235
CSHCN whose conditions cause financial problems for the family	25.4	20,372
CSHCN whose families spend 11 or more hours per week providing or coordinating health care	15.3	11,500
CSHCN whose conditions cause family members to cut back or stop working	28.3	22,611

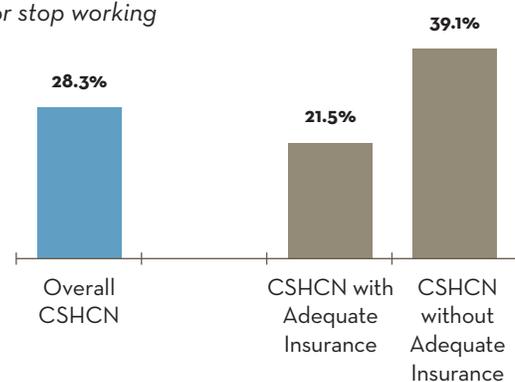
### Impact on the Family\*:

CSHCN whose conditions cause financial problems for the family



### Impact on the Family\*:

CSHCN whose conditions cause family to cut back or stop working



\* National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 02/15/2013 from [www.childhealthdata.org](http://www.childhealthdata.org).

**Our Work:** The Nevada Family-to-Family Healthcare Information and Education Center is funded by the Maternal and Child Health Bureau to provide statewide support to families of children and youth with special health care needs by:

- ▶ Assisting families as they navigate public and private systems, including health systems and insurance plans,
- ▶ Assisting families in accessing services and resources for their children and in partnering with providers and caregivers,
- ▶ Listening to families as they describe their encounters with systems and helping guide them to possible solutions,
- ▶ Working with families, health care providers, public and private agencies, and advocacy or support groups to promote family-centered care and medical homes for children with special health care needs,
- ▶ Promoting discussion and linkages among families, providers, managed care programs, and government to better serve the health care and related needs of children and families in Nevada.

## By The Numbers

**From June, 2011 through May, 2012, Family TIES of Nevada reported:**

	FAMILIES	PROFESSIONALS
Total People Served	3,867	3,734
People Served through 1-1 Assistance and Trainings	1,401	2,287
People Reached through Newsletters	840	840
People Reached through Listservs	1,126	606
Materials Disseminated	12,669	

## % Families reporting value of Family TIES' assistance /information/resources in:

	NOT USEFUL	SOMEWHAT USEFUL	USEFUL	VERY USEFUL	EXTREMELY USEFUL
Helping them Partner in Decision-Making		2%	22%	46%	30%
Finding and/or Learning about Community Services			24%	46%	30%
Feeling Confident in Getting Health Care and Services Needed by Child		2%	28%	43%	28%

## 2011-2012 Activity Highlights

- At a special invitation by U.S. Senator Harry Reid's office, we participated in the 2nd Whitehouse **Hispanic Community Action Summit**.
- To increase awareness of our F2F HIC, we established a partnership with **Nevada Health Centers**, a Federally Qualified Health Center with 19 health center sites across the state.
- We continued our outreach at **Helping Kids Clinic** in Las Vegas, and developed a pilot project with **Nevada Early Intervention Services**.
- As a member of the Steering Committee for the **NV Statewide Maternal and Child Health Coalition**, we support its mission - to improve the physical and mental health, safety and well-being of the maternal and child health population in Nevada including children with special health care needs.
- Under a Systems Change grant from the **Nevada Governor's Council on Developmental Disabilities**, we are reaching more families of CYSHCN, people with developmental disabilities, and professionals/providers. We were also selected to serve as the Lead Planning Agency for the **Nevada Disabilities Conference 2013**.
- As a result of our expanded outreach and family/community/professional partnerships; requests for information, assistance and referrals **increased by 25%** since 2010.

## 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

*"I refer many families to Family TIES and repeatedly receive excellent feedback on how helpful they are. I enjoy working with their staff and find them to be outstanding in areas such as Advocacy and Parent Support."*

**Rosemary Meza, Bi-lingual Outreach Coordinator & Case Mgr  
Southern Nevada Center for Independent Living**

*"Through Family TIES, I can help the families of children with special health care needs navigate the system while getting support from other parents who have 'been there'. They are an outstanding resource."*

**Johanna S. Fricke, M.D., Developmental/Behavioral Pediatrics, Healthy Minds, LLC, Las Vegas, NV**



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