

# Children with Special Health Care Needs in IDAHO

## 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 Member in Idaho:

*"My youngest child has autism, epilepsy, and a chromosome disorder. The challenges are more than one family can bear at times and yet I always know that I can connect and search for resources with the help of the IPUL staff. IPUL empowers parents and guides them to find, educate and apply for needed resources. In my opinion the best part of this is that IPUL doesn't just do the work for you, they teach families how to help themselves. These people don't just study up on how to do their job; many of them live with children with special needs. The difference that this makes for families is incredible. They understand the emotional side of the family, it is not just a passion on their part it is compassion because they have shared many of our challenges."*

## By the Numbers: CSHCN in Idaho:

Prevalence of Children with Special Health Care Needs (CSHCN), among all children age 0-17	12.7%	53,280
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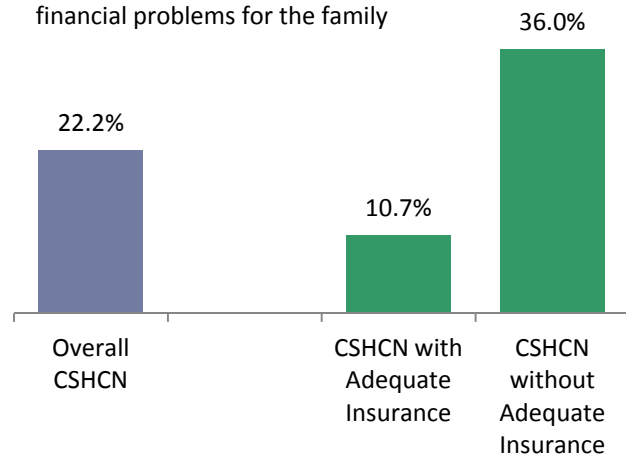
	% of CSHCN	# of CSHCN
Currently insured CSHCN whose insurance is inadequate	37.5	18,693

### Impact of CSHCN on the Family:

CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year per child	23.6	12,197
CSHCN whose conditions cause financial problems for the family	22.2	11,650
CSHCN whose families spend 11 or more hours per week providing or coordinating health care	14.0	7,072
CSHCN whose conditions cause family members to cut back or stop working	24.7	13,000

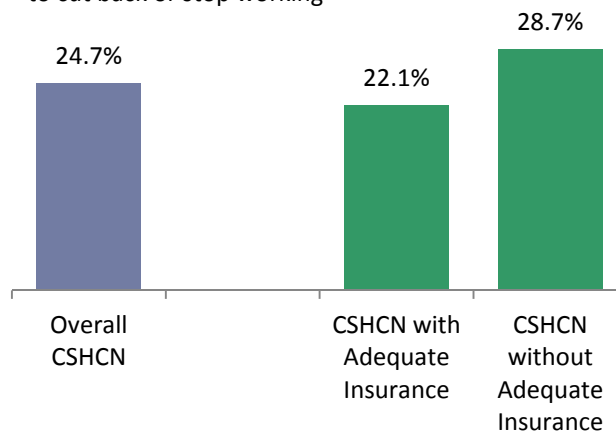
#### Impact on the Family\*:

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 01/19/2012 from [www.childhealthdata.org](http://www.childhealthdata.org).

# Idaho Parents Unlimited, Inc., a Family-to-Family Health Information and Education Center

## Our Work:

The Family to Family Health (F2F) Information Center works at Idaho Parents Unlimited, Inc. works to help sustain the health and well-being of Idaho’s families, their children and youth with special health care needs. The program values family-centered care and honors the strengths, cultures, traditions and expertise in the family/professional partnership. The F2F project assists families with:

- Finding payment for medical care
- Obtaining help navigating public health care financial problems
- Seeking dialogue with other parents in similar situations
- Looking for information to find community resources
- Linking to an established clearing house of information about health care issues
- Obtaining one to one assistance finding information and getting referrals for specific health problems
- Advocating for their child
- Locating and attending workshops and obtaining materials about related health care issues, including information tailored to assist youth and parents in transition to adulthood
- Collaborating with Idaho's Family Voices and the national network of Family Voices, which are the technical assistance arms of F 2F
- Gaining empowerment to make changes in established federal, state, and local governing systems

## By The Numbers

From June, 2010 through May, 2011, Idaho Parents Unlimited, Inc. reported:

	Families	Professionals
<b>Total People Served</b>	<b>7,654</b>	<b>5,126</b>
<b>People Served through 1-1 Assistance and Trainings</b>	<b>348</b>	<b>255</b>
<b>People Reached through Newsletters</b>	<b>6,176</b>	<b>3,785</b>
<b>People Reached through Listservs</b>	<b>1,130</b>	<b>1,086</b>

## As a Result of Assistance /Training Provided by Idaho Parents Unlimited, Inc.:

<b>% Families Reporting Better Able to Partner in Decision-Making</b>	<b>100%</b>
<b>% Families Reporting Better Able to Find and/or Learn about Community Services</b>	<b>98%</b>
<b>% Families Reporting More Confidence in Getting Health Care and Services Needed by Child</b>	<b>100%</b>

### 2010-2011 ID F2F HIC Activity Highlight

*“The area in which we had the greatest impact was through a wonderful partnership with our Children’s Special Health Care Program which created **Transition Materials for Youth with Special Health Care Needs** and their families. In September, a video created by IPUL Youth Volunteers on CYSHCN Transition was shown at the Council for Exceptional Children Conference which is attended by several hundred Educators from around the state. More than 1,000 Transition kits were requested at this conference. We will continue to promote the Transition Materials and work with our Youth representatives to address their health care information needs and outreach.”*

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

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