



ONE in FIVE

Families with Children Across the US Has at Least One Child with Special Health Care Needs



14.6 million children ages 0-17 (almost 20% of all children) in the US have a special health care need (SHCN), such as:

- autism
- cerebral palsy
- developmental delay
- intellectual disabilities
- depression,
- learning disabilities
- epilepsy

More Health Care Utilization than children without special health care needs

- 4 times # of hospitalizations**
- 7 times # days of hospital care**
- 7 times # of annual visits to providers**
- 5 times # of prescriptions**

Impact



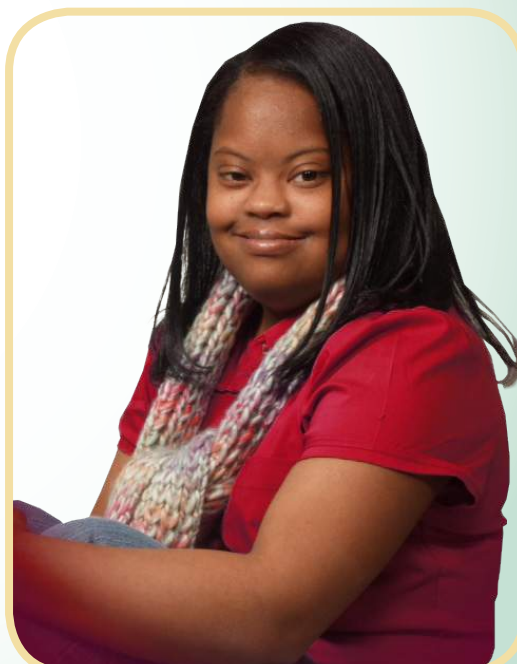
- Daily activities of 66% of children with SHCN are consistently or moderately affected
- Majority of children with SHCN have co-occurring health conditions and require multiple specialized services



- Families of 22% of children with SHCN pay more than \$1000 per year in out-of-pocket expenses
- Families of 25% of children with SHCN stopped working or cut back their hours to care for their child



- Health care expenses are 4 times greater than children without SHCN
- The health status and needs of children with SHCN increase in impact and complexity as they grow





FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS (F2FS)

- Family-led organizations in each state and DC
 - Help families connect with programs and work with providers
 - Help policy makers understand family issues
 - In FY 2014, F2Fs served over 1 million families and 377 thousand professionals
- 92% families report that the F2F helps them partner in decision-making
- 93% families report that the F2F helps them navigate services and feel more confident



PROGRAMS & SERVICES

- 52% children with SHCN - private insurance only
- 40% children with SHCN - public insurance only
- 8% children with SHCN - both private & public
- 45% children with SHCN require specialist care

“Medical bills, medications, specialized formulas, and lost wages far outweigh the costs of standard living. This is why Medicaid matters.”

- a mom in Indiana



PROVIDER PRACTICES

- Medical homes improve health outcomes
 - Family-centered care (FCC) results in fewer unmet health care needs and increased satisfaction with care
- 53% children with SHCN do not receive coordinated, ongoing, comprehensive care within a medical home
- 35% children with SHCN do not receive family-centered care(FCC)
- Children with SHCN of diverse racial, ethnic, and socio-economic backgrounds are less likely to receive FCC



FAMILY VOICES

- Assists families and family leaders in every state & D.C.
- Provides tools & resources to improve care
- Monitors & informs policy

- 76% family leaders indicate Family Voices impacts their work in health care reform
- 75% family leaders indicate Family Voices increases their cultural & linguistic competence
- 71% family leaders indicate Family Voices impacts their work in helping families partner