Children & Youth with Special Health Care Needs in Iowa

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About 17% of children and youth in Iowa have a special health care need.

23% of CYSHCN in Iowa were limited because of physical health, and 8% were limited because of behavioral/emotional health.

In Iowa, 17%, or approximately 127,000 children and youth have a special health care need. This policy brief draws information about Children and Youth with Special Health Care Needs (CYSHCN) in Iowa from the Iowa Child and Family Household Health Survey, a statewide panel study of the health and well-being of children in Iowa families.

Data were collected using telephone interviews regarding over 3200 children in Iowa, completed in the spring and summer of 2000. This study was a collaboration between the University of Iowa Public Policy Center (PPC), the Iowa Department of Public Health, the Iowa Child Health Specialty Clinics and the University of Northern Iowa. It was funded by a grant from the US Bureau of Maternal and Child Health and the Iowa Department of Public Health.

CYSHCN included those who had a medical, behavioral or other health condition lasting or expected to last at least 12 months, and one of the following criteria:
- greater limitations in daily functioning
- needed prescription medications
- need for extra health services
- needed special therapies
- needed treatment or counseling for emotional, developmental, or behavioral problems

Seventy-five percent of CYSHCN were reported to be in excellent or very good health, compared with 94% of children without special health care needs. As Figure 1 shows CYSHCN were also more likely to be in fair or poor health.

CYSHCN were more likely to have limitations in activity due to physical and/or behavioral/emotional health than did other children. Twenty-three percent of CYSHCN were limited because of physical health, compared to 8% of other children. Eleven percent of CYSHCN were limited due to behavioral/emotional health compared to 1% of other children.

Chronic conditions of CYSHCN included asthma (24%), chronic allergies or sinus problems (21%), Attention Deficit Hyperactivity Disorder (ADHD) (19%), behavioral problems (not including ADHD or depression) (19%), and depression (4%).
Health insurance status

CYSHCN were more likely to have health insurance at the time of the survey: 3% of CYSHCN were uninsured at the time of the survey, whereas 7% of other children lacked insurance. Ten percent of currently insured CYSHCN were uninsured at some point during the past year, which is double the rate of other children.

Among insured children, 78% of CYSHCN had private insurance, while 90% of other children were privately insured. Twenty percent of CYSHCN were covered by Medicaid or Iowa's SCHIP program (hawk-i), compared with 9% of other children.

Parents of CYSHCN were more likely than parents of other children to worry about paying for their child's health care (41% vs 32%), and 15% of parents of CYSHCN worried 'a great deal'.

Access to medical care and use of services

Having a regular source of medical care is one important aspect to accessing medical care. CYSHCN were as likely as other children to have one main personal doctor or nurse (90%). However, among youth ages 10-17, CYSHCN were more likely to have a regular source of care than other children. Ninety percent of CYSHCN ages 10-14 had a regular source of care compared to 86% of others, while in the 15-17 age category, 94% of CYSHCN and 86% of others had a regular source of care.

CYSHCN were much more likely to have needed medical care (72%) than children without a special health care need (48%). CYSHCN were more likely to have been prevented from receiving care in the past year (7% vs 2% of others). Cost was the main reason for being prevented from receiving care for both CYSHCN and children without special health care needs. CYSHCN were more likely to have been stopped from receiving care because insurance did not cover the needed care (38% vs 12%).

CYSHCN had more physician visits (47% had 5 or more visits vs 19% of others) and sought treatment in an emergency room more frequently (44% vs 28%). Six percent of CYSHCN had been to a hospital emergency room more than 5 times in the past year.

CYSHCN were more likely to have had a preventive visit (82% vs 76%) in the past year, and were more likely to have received anticipatory guidance (39% vs 26%) including age specific information about car seats, seat belts, bicycle safety or nutrition counseling.

A majority (60%) of CYSHCN needed care from a specialist in the past year compared to 23% of children without special health care needs. CYSHCN were more than twice as likely to have a problem getting needed care from a specialist (25% vs 11%).

Thirty percent of CYSHCN in Iowa needed behavioral or emotional care, while only 4% of other children needed these services. Twelve percent of CYSHCN were unable to get needed behavioral or emotional health care.
Access to dental care and use of services

Dental care was received by 82% of CYSHCN, compared with 73% of children without special health care needs. Parents of CYSHCN were more likely to say that their child needed dental care (57% vs 44%).

CYSHCN were more likely to have dental insurance coverage than other children (84% vs 73%), however, they were also more likely to have unmet dental care needs (11% vs 7%). Most of the unmet need was related to cost, however more than twice as many CYSHCN reported that the unmet need was related to trouble getting a dental appointment (55% vs 22%).

Issues about child care

About half of children under age 10 in Iowa received childcare from someone other than a parent. Childcare settings differed between CYSHCN and those without special health care needs.

Among children under age 4, CYSHCN were more likely to receive care from a sibling (8% vs 2%), and were less likely to be cared for by a grandparent (9% vs 16%). CYSHCN over age 4 were more likely to be in a daycare setting (27% vs 19%) and were more likely to be with an unrelated babysitter (37% vs 26%). Most parents were very satisfied with their childcare arrangements (93% of CYSHCN and 95% of others).

About one third of parents of CYSHCN had trouble finding childcare because of the special needs of their child.

School performance and extracurricular activities

Parents of school-aged children were asked about school performance, expectations, and engagement in school. Half of CYSHCN were rated as having excellent or very good performance at school, while the school performance of almost three-quarters of others were rated excellent or very good. CYSHCN were reported as having fair or poor school performance more frequently (22% vs 7%). Most parents would like to see their children go to a four-year college, but a quarter of CYSHCN had parents who hoped their child would receive a two-year degree compared with 11% of the parents of children without special health care needs.

A series of 4 questions was used to evaluate the degree to which school-age children in Iowa were engaged in school. CYSHCN were much more likely to be identified as having low school engagement (29% vs 10%). Twenty-eight percent of CYSHCN in Iowa were considered to have high engagement in school, while 44% of children without special health care needs had high engagement in school.

Most school-age children in Iowa (83%) participated in activities such as clubs, teams sports, band, or a religious group. CYSHCN were about as likely as other children to have participated in these activities (81% vs 84%).

CYSHCN were more likely to have dental insurance, but were also more likely to have problems receiving needed dental care.

Parents of one-third of CYSHCN who needed childcare had trouble finding it because of their child’s health care needs.

Most school-age children in Iowa participate in extracurricular activities, regardless of their special health care need status.
The family environment

Ten percent of children in Iowa lived in a household where substance use was reported to be a problem. CYSHCN were much more likely to live in a household with a reported substance use problem (16% vs 9% of other children). CYSHCN were twice as likely to live in a household where substance use was reported to be a ‘big’ problem (6% vs 3%).

CYSHCN were less likely to live in a household where the parent’s marital relationship was rated as excellent or very good (79% vs 86%).

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