

System of Care for CSHCN CSHCN meeting all age-relevant core outcomes

Effective promotion of health and health services for children with special health care needs (CSHCN) requires a system of care that is integrated, comprehensive, coordinated, family centered and consistent across the life course (or lifespan). Ideally, these systems are easy to navigate and foster positive experiences between families and health service providers. Advancing integrated systems of care for CSHCN and their families is a national mandate under Public Law 101-239 and is a priority reflected in the Healthy People goals set forth by the U.S. Department of Health and Human Services from 2000 to 2020. To help determine progress towards these goals, the Federal Maternal and Child Health Bureau established the following six core outcomes that facilitate integrated systems of care for CSHCN:

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|--------------------------------|---|
| 1. Partners in Decision-Making | 4. Early and Continuous Screening |
| 2. Medical Home | 5. Ease of Community-Based Service Use |
| 3. Adequate Health Insurance | 6. Transition to Adulthood (age 12-17 years only) |

The National Survey of Children with Special Health Care Needs (NS-CSHCN) was designed to provide information on the CSHCN population and to assist in the measurement of these core outcomes. Using low-threshold criteria for meeting each core outcome, an “overall system of care” summary measure is calculated by evaluating the number of CSHCN meeting all age-appropriate core outcomes: Outcomes #1-5 for CSHCN age 0-11 and Outcomes #1-6 for CSHCN age 12-17. Nationally, 20.2% of CSHCN age 0-11 met all 5 core outcomes, with prevalence ranging from 13.0% to 27.5% across states. CSHCN age 12-17 are less likely to meet all 6 core outcomes at the national level (13.6%), with prevalence ranging from 7.5% to 22.2% across states for this age group. Assessment of the variation between states and within demographic or other subgroups of CSHCN is critical to developing appropriate interventions and policy responses.

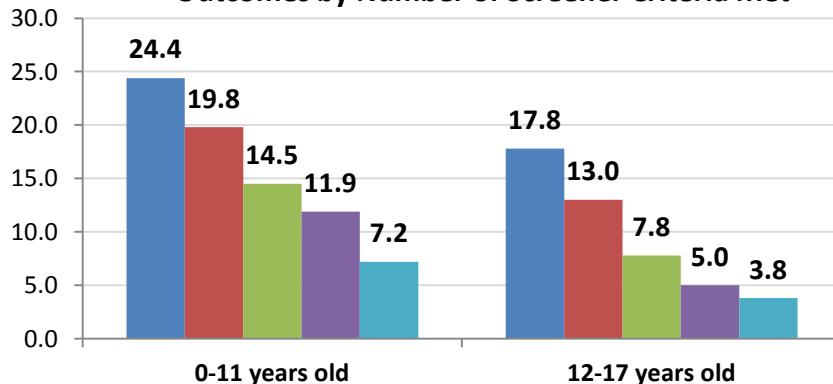
Age 0-11 years:

12.7%	15.3%	16.1%	20.2%	25.3%
CSHCN with one or more EBD* issues	CSHCN with more complex needs	Publicly insured CSHCN	All CSHCN age 0-11	Privately insured CSHCN

Age 12-17 years:

6.2%	6.4%	8.9%	13.6%	19.2%
Publicly insured CSHCN	CSHCN with one or more EBD* issues	CSHCN with more complex needs	All CSHCN age 12-17	Privately insured CSHCN

Percentage of CSHCN Meeting all Age-Relevant Core Outcomes by Number of Screener Criteria Met



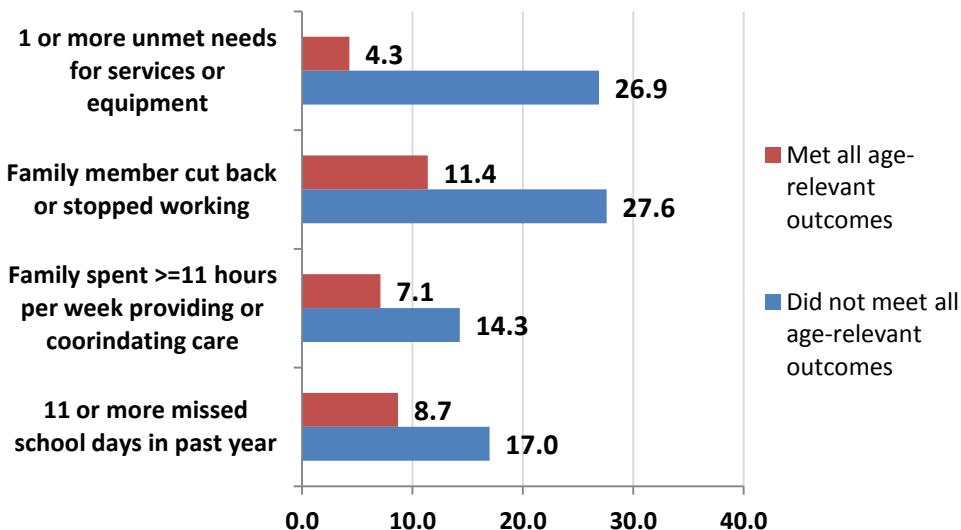
- The CSHCN Screener includes five types of consequences, selected among numerous possible health service need consequences children with ongoing conditions may experience: (1) prescription medication use, (2) above routine service use, (3) specialized therapy use, (4) treatment for EBD* and (5) limitations in daily activities compared to similar age children.
- The more of these criteria CSHCN meet, the less likely he or she is to be served by a system of care that meets all age-relevant core outcomes.

*Emotional, behavioral or developmental

**National and state-level prevalence of all outcomes by demographics & subgroups are available online at childhealthdata.org

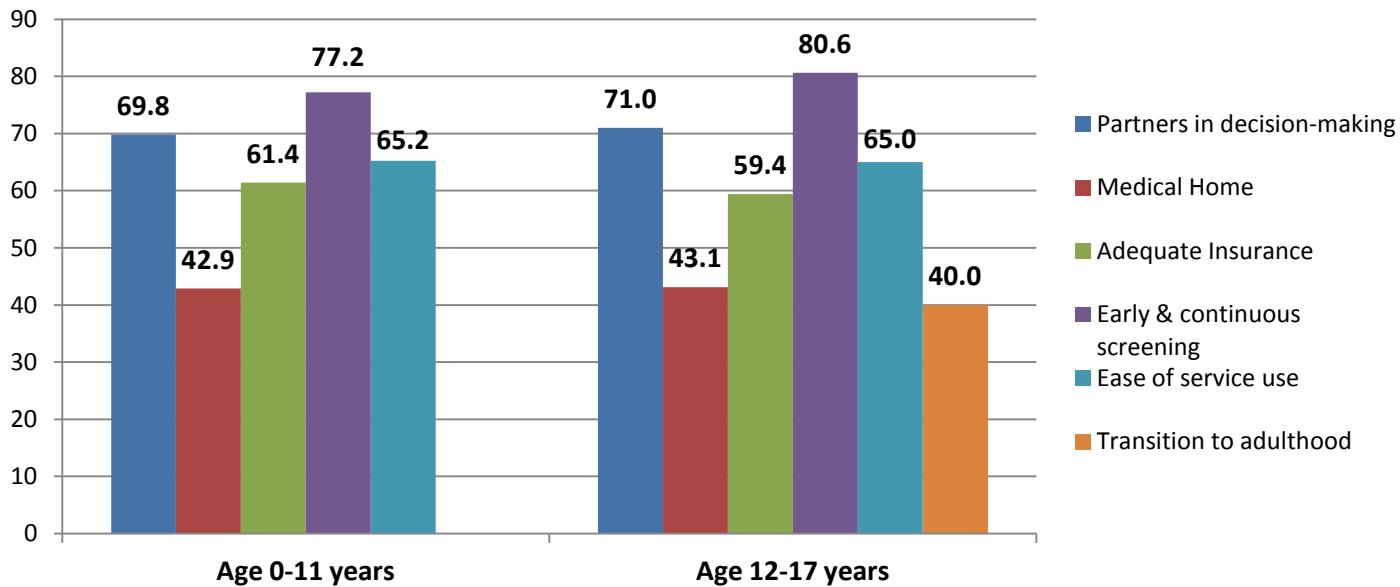


Experience with care, impact on the family and missed school for CSHCN age 0-17 years who did and did not meet all age-appropriate core outcomes



- CSHCN served by systems of care that meet all age-appropriate core outcomes are less likely to have unmet needs, have a smaller impact on the family and miss fewer school days than CSHCN whose care does not meet all age-relevant core outcomes.

Percentage of CSHCN Meeting Each Core Outcome



- Core Outcome #2: Medical Home and Core Outcome #6: Transition to Adulthood (CSHCN age 12-17 years only) are the two outcomes least likely to be met.
- For both age groups, more CSHCN met Outcome #4: Early and Continuous Screening than any other outcome.

Trending Across Survey Years: Some of the outcomes have changed between survey years. Therefore, system of care data for 2009/10 cannot be compared to 2005/06 or 2001 data.