

Outcome #1

Families are partners in decision making at all levels

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:

- | | |
|--------------------------------|--|
| 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 |

The National Survey of Children with Special Health Care Needs (NS-CSHCN), which has been conducted every four years since 2001, is designed to provide information on the CSHCN population and to assist in the measurement of these core outcomes. The survey measures each core outcome with low-threshold criteria. Outcome #1 is measured through questions that assess the extent to which health professionals engage families in decision-making about their child's health care. Based on data from the 2009/10 NS-CSHCN, 70.3% of CSHCN nationwide meet Outcome #1, with states ranging from 61.8% - 77.6%. Assessment of the variation between states and within demographic or other subgroups of CSHCN is critical to developing appropriate interventions and policy responses.

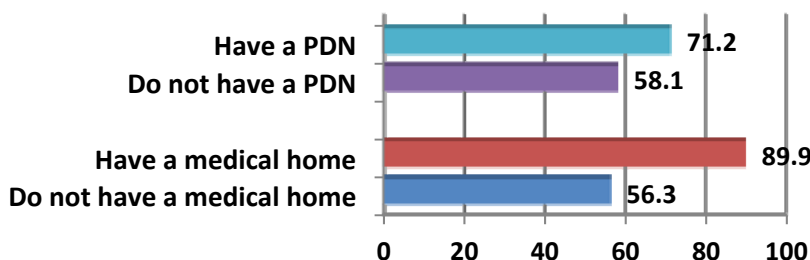
Measurement

CSHCN meet Outcome 1 when the respondent answers usually or always to all four of the following questions:

We want to know about how [S.C.]'s doctors or other health care providers work with you to make decisions about [his/her] health care services and treatment. During the past 12 months...

1. How often did [S.C.]'s doctors or other health care providers discuss with you the range of options to consider for [his/her] health care or treatment? (C6Q21)
2. How often did they encourage you to ask questions or raise concerns? (C6Q22)
3. How often did they make it easy for you to ask questions or raise concerns? (C6Q23)
4. How often did they consider and respect what health care and treatment choices you thought would work best for [S.C.]? (C6Q24)

Proportion of CSHCN Meeting Outcome #1 by Presence of a Medical Home and Personal Doctor or Nurse



- CSHCN with a personal doctor or nurse (PDN) are more likely to receive care where their families are partners in decision making than CSHCN without a PDN.
- CSHCN with a medical home are more likely to meet Outcome #1 than CSHCN without a medical home.

*Emotional, behavioral or developmental

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

57.6%
Uninsured
CSHCN

61.5%
CSHCN with one or
more EBD* issues

65.9%
CSHCN with more
complex needs

70.3%
All CSHCN

76.0%
Privately insured
CSHCN



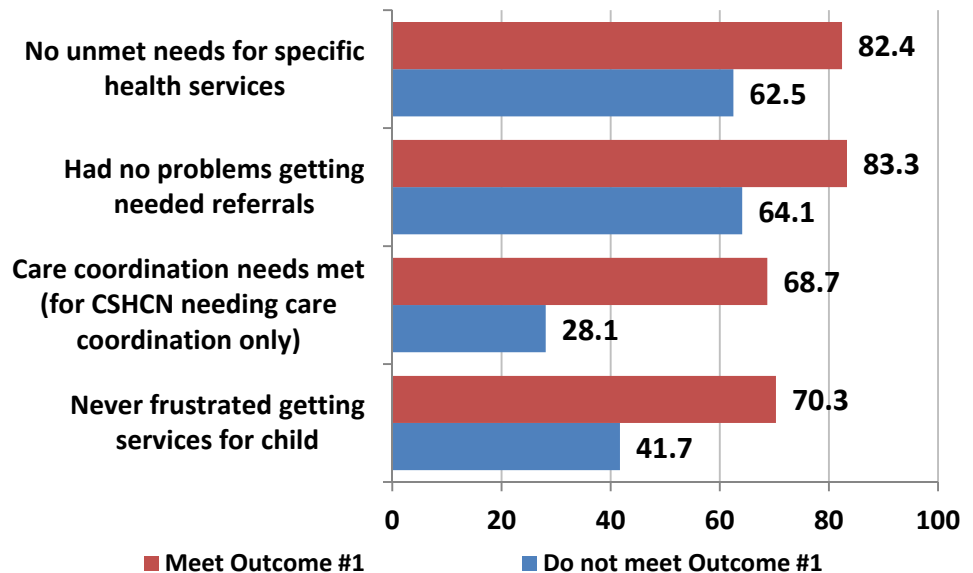
Setting the stage for optimal health trajectories.

A partnership between a child's family and their health care providers allows for an open and intentional dialogue about his or her unique health needs. This leads to individualization of care and the ability to identify factors that may negatively affect his or her health. It also gives children and their families the support they need during critical periods of development. However, only about 70% of CSHCN meet this core outcome. Vulnerable CSHCN, especially those with functional limitations and those living in poverty, are even less likely to receive care in which families are partners in decision making.

Trending Across Survey Years:

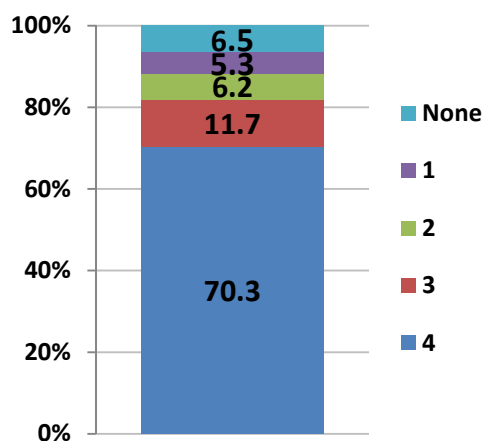
Measurement changed significantly for 2009/10 NS-CSHCN, and therefore cannot be compared to 2001 or 2005/06 NS-CSHCN survey findings.

Experience with care for CSHCN who do and do not meet Outcome #1



- CSHCN who meet Outcome # 1 have a lower probability of experiencing frustration seeking services or having unmet needs for specific health services than CSHCN who do not meet Outcome # 1
- CSHCN who meet Outcome #1 have a higher probability of having their care coordination needs met and having no problems getting needed referrals than CSHCN who do not meet Outcome # 1

Number of Shared Decision Making Elements Met



The chart to the left shows the percentage of parents reporting various number of elements of shared decision making elements met their child's care. Nationally, 6.6% of CSHCN have families who experience no elements of shared decision making.

Taking it a Step Further

The following are questions relating to Outcome #1 that cannot be answered by this national survey data but are important to consider when evaluating how early and continuous screening can best work to improve the health and well-being of CSHCN:

- Current measurement is physician-focused -- are families working to encourage these critical conversations?
- Do families have the support they need to play the most positive role possible in their child's development?
- What do health care providers do to educate families on how they can best support their child's development?
- What is the family doing in the day-to-day life of their child to promote or maintain health?
- Are families involved in the policy decisions that affect them?

Outcome #2

Coordinated, ongoing, comprehensive care within a medical home

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, families of CSHCN can easily navigate such a system, leading to positive experiences seeking care and interacting with service providers. Advancing integrated care systems for CSHCN and their families is a national mandate under Public Law 101-239 as well as 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 determine progress toward an integrated system of care for all CSHCN, the Federal Maternal and Child Health Bureau established the following six core outcomes:

1. Partners in Decision-Making
2. Medical Home
3. Adequate Health Insurance
4. Early and Continuous Screening
5. Ease of Community-Based Service Use
6. Transition to Adulthood

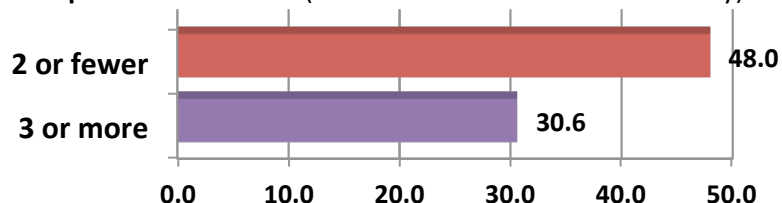
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Measurement

CSHCN meet Outcome 2 when the respondent answers that their child:

1. Has at least one personal doctor or nurse (PDN, C4Q02A)
2. Received family-centered care in the previous 12 months (C6Q01-C6Q06)
 - Health providers usually or always spend enough time with them, listen well, are sensitive to family values and customs, provide needed information and make family feel like a partner in care
3. Has no problems getting referrals when needed (C5Q11, C4Q07)
4. Has usual source or sources of sick and well care (C4Q01-D, C4Q01-2)
5. Receives effective care coordination (C5Q05-06, C5Q09-10, C5Q12-17)
 - Saw at least 2 medical providers and usually or always got all needed help coordinating care AND, if applicable, was very satisfied with the communication between providers and school/daycare and/or between primary provider and other medical providers

Percent of CSHCN with a Medical Home by Number of Reported Conditions⁺ (of Those Asked About in the Survey)



• CSHCN with more reported conditions have a lower probability of having a medical home than those with fewer reported conditions.

⁺As measured in the 2009/10 NS-CSHCN, 70.9% of CSHCN have 2 or fewer and 29.1% of CSHCN have 3 or more of the conditions asked about in the survey

24.2%

Uninsured CSHCN

28.8%

CSHCN with one or more EBD* issues

34.6%

CSHCN with more complex needs

43.0%
All CSHCN

51.2%

Privately insured CSHCN

*Emotional, behavioral or developmental

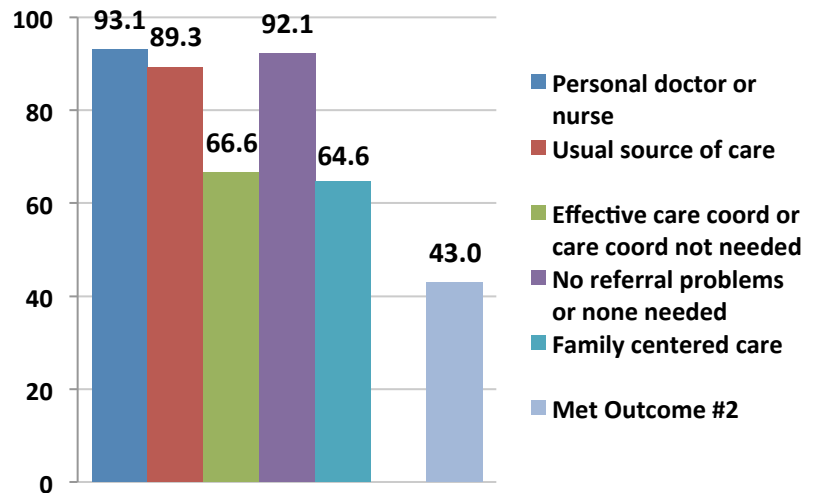
National and state-level prevalence of all outcomes by demographics & subgroups are available online at childhealthdata.org

shared ownership
 culturally acceptable
continuity well-being
 family-centered collaboration
 shared decision-making
 lasting relationships
OUTCOME 2: MEDICAL HOME
 improve health outcomes
 care coordination
personalized
 usual source of care
 preventive visits
 affordable, accessible
integrated

Supporting whole-person development through integration and stability.

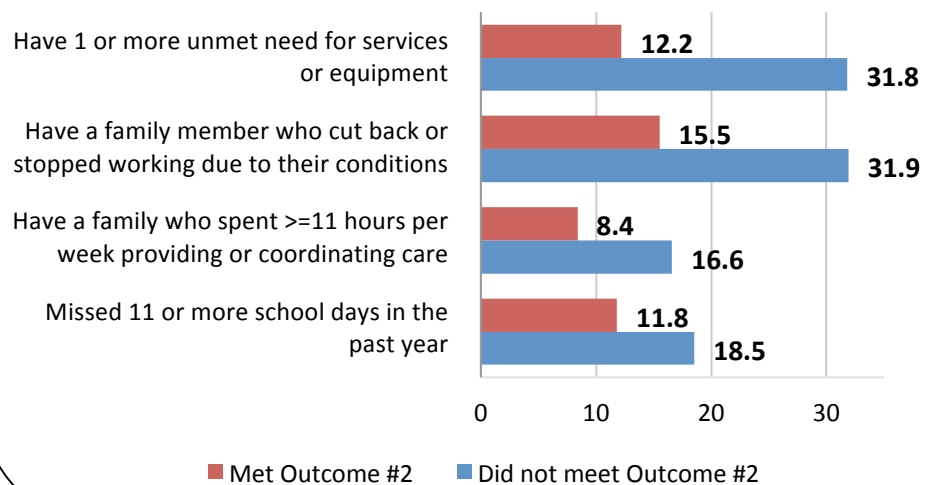
The medical home ensures that children have easy and timely access to appropriate, individualized and comprehensive health care. It means families are given the information and framework to be actively engaged in their child's care. It also gives children support and consistency throughout childhood's diverse developmental stages. Medical homes provide youth with appropriate preventive care with a focus on integrated services and positive long-term outcomes. However, less than half of all CSHCN have a medical home. Children with more complicated needs are substantially less likely to have a medical home, although they have great potential to benefit from one.

Percent of CSHCN Meeting Medical Home Sub-Components



- Effective care coordination and family centered care are the two medical home subcomponents least likely to be met.

Experience with care, impact on the family and missed school for CSHCN with and without a medical home. Percent of CSHCN who...



Trending Across Survey Years: Measurement changed just slightly for 2009/10 NS-CSHCN, and therefore can be compared to 2005/06 NS-CSHCN survey findings.

Taking it a Step Further:

The following are questions relating to Outcome #2 that cannot be answered by this national survey data but are important to consider when evaluating how early and continuous screening can best work to improve the health and well-being of CSHCN:

1. Is the medical home consistent and continuous?
 - Does child have access to the same health care providers within their medical home through changes in income, jobs and insurance status?
2. Do families have a choice of providers so that they can find the best fit?
3. Are families educated about all of the resources and options available to them within their community?

Outcome #3 Adequate insurance to cover needed services

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, families of CSHCN can easily navigate such a system, leading to positive experiences seeking care and interacting with service providers. Advancing integrated care systems for CSHCN and their families is a national mandate under Public Law 101-239 as well as 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 determine progress toward an integrated system of care for all CSHCN, the Federal Maternal and Child Health Bureau established the following six core outcomes:

- Partners in Decision-Making
- Early and Continuous Screening
- Medical Home
- Ease of Community-Based Service Use
- Adequate Health Insurance
- Transition to Adulthood

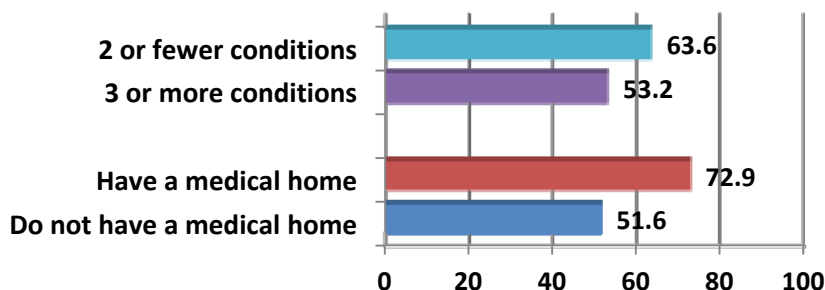
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Measurement

CSHCN meet Outcome 3 when the respondent answers that:

1. Their child was insured at the time of the survey and has had no gaps in coverage in the previous 12 months (UNINS, UNINS_YR)
2. Their child's health insurance offers benefits that usually or always meet the child's needs (C8Q01_A)
3. The non-covered insurance charges are usually or always reasonable (C8Q01_B)
AND
4. Their child's health insurance usually or always allows him or her to see needed providers (C8Q01_C)

Percentage of CSHCN Meeting Outcome #3 by Number of Reported Conditions of Those Asked About in the Survey and Presence of a Medical Home



- CSHCN with 3 or more of the conditions asked about in the survey (representing 29.1% of CSHCN) have a lower probability of meeting Outcome #3 than those with 2 or fewer of the conditions asked about in the survey (representing 70.9% of CSHCN).
- CSHCN with a medical home are more likely to meet Outcome #3 than CSHCN without a medical home.

*Emotional, behavioral or developmental

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

53.6%	55.7%	60.6%	63.4%	68.1%
CSHCN with one or more EBD* issues	CSHCN with more complex needs	All CSHCN	Privately insured CSHCN	CSHCN qualified on Rx use only

reduce burden on families

OUTCOME 3: ADEQUATE INSURANCE

critical for lifelong health

affordable
 reduce stress consistent
 accessible
 equitable access to quality care

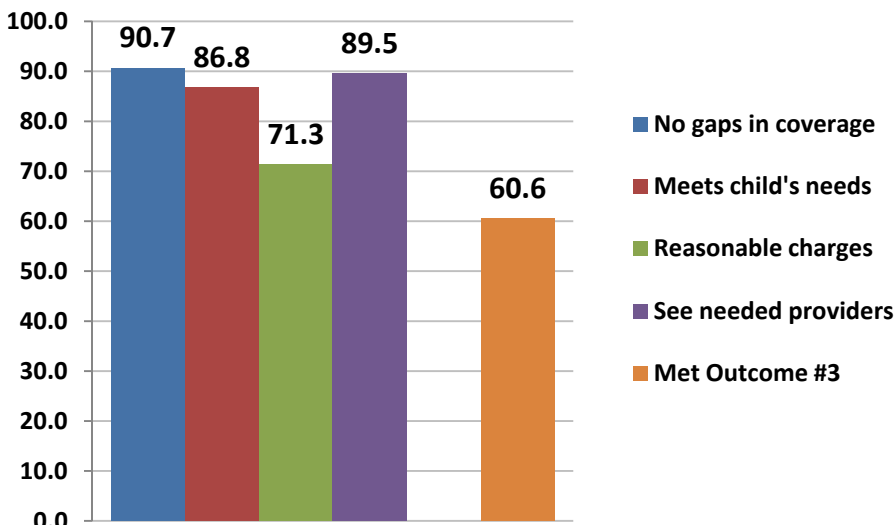
reliable
 reduce disparities
 good coverage

ability to get needed care

A foundation for adequate care.

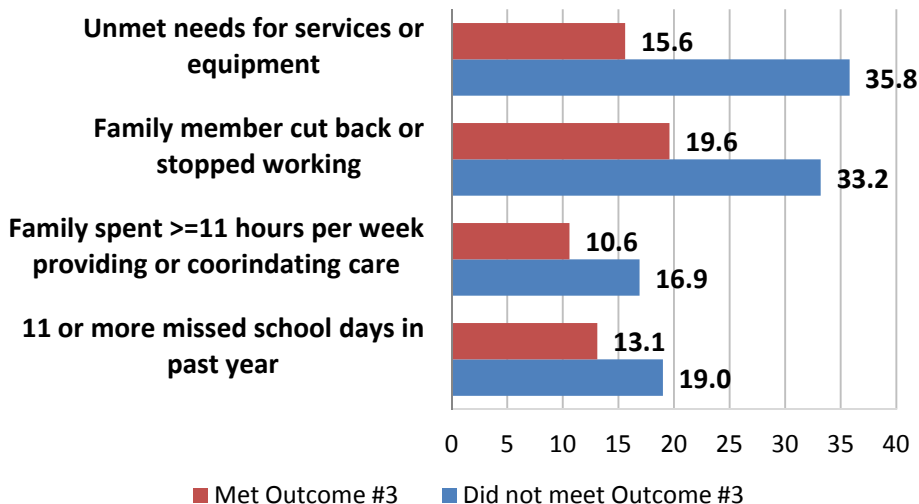
Children with nonexistent, inconsistent or inadequate health insurance are less likely to receive the care they need and thus suffer greater consequences from their health conditions. Adequate health insurance plays a substantial role in ensuring access to family-centered care and a medical home. Additionally, health insurance coverage and adequacy are related to underlying social factors such as income and employment. Children with inadequate or no health insurance are also more likely to face greater stress and adversity related to poverty or education. The combination of these factors makes them especially vulnerable to the health and psychological consequences of unmet needs. All children need adequate insurance, yet nearly 4 in 10 CSHCN do not meet this outcome.

Percentage of CSHCN Meeting Adequate Insurance Sub-Components



- Reasonable costs of non-covered charges is the component of Outcome #3 least likely to be met.

Experience with care, impact on the family and missed school for CSHCN with and without adequate insurance



Trending Across Survey Years: Measurement has not been changed and this outcome in 2009/10 can be compared to survey results in 2005/06 and 2001.

Taking it a Step Further:

The following are questions relating to Outcome #2 that cannot be answered by this national survey data but are important to consider when evaluating how early and continuous screening can best work to improve the health and well-being of CSHCN:

- Does insurance give a choice in providers?
- Does insurance cover the services needed for optimal health?
- Is insurance easy to use and navigate? Does it cause stress?
- What, if anything, do families give up to pay for CSHCN's medical needs even if costs not covered by insurance are reasonable?
- Do families avoid seeking certain types of care for their CSHCN because they don't know if insurance covers it?

Outcome #4

CSHCN who are screened early and continuously for special health care needs

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, families of CSHCN can easily navigate such a system, leading to positive experiences seeking care and interacting with service providers. Advancing integrated care systems for CSHCN and their families is a national mandate under Public Law 101-239 as well as 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 determine progress toward an integrated system of care for all CSHCN, the Federal Maternal and Child Health Bureau established the following six core outcomes:

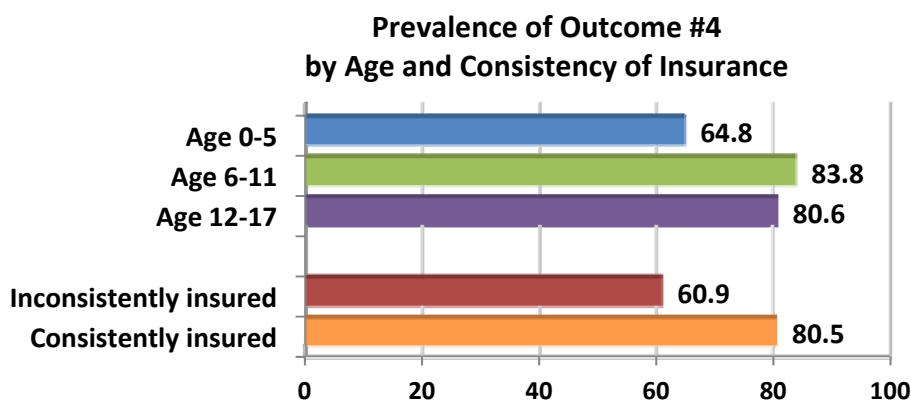
1. Partners in Decision-Making
2. Medical Home
3. Adequate Health Insurance
4. Early and Continuous Screening
5. Ease of Community-Based Service Use
6. Transition to Adulthood

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Measurement

For CSHCN to meet Outcome 4, they must have had preventive medical and dental care in the prior 12 months (visits where screening may have occurred). It is based on the following two questions:

1. [During the past 12 months / Since [his/her] birth], how many times did [child] receive a well-child check-up, that is a general check-up, when [he/she] was not sick or injured? (K4Q20)
2. [During the past 12 months / Since [his/her] birth], how many times did [child] see a dentist for preventive dental care, such as check-ups and dental cleanings? (age 1-17 years, K4Q21)



- CSHCN age 0-5 years are least likely to receive at least one preventive medical visit and one preventive dental visit in the past 12 months, which is due to the low rates of preventive dental visits among CSHCN age 1-5 years.
- CSHCN with one or more periods of uninsurance in the past year are significantly less likely to meet Outcome #4 as measured in the 2009/10 NS-CSHCN.

*Emotional, behavioral or developmental (EBD) issues

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

51.4%

Uninsured
CSHCN

77.3%

CSHCN with more
complex needs

78.6%

CSHCN with one or more
EBD* issues

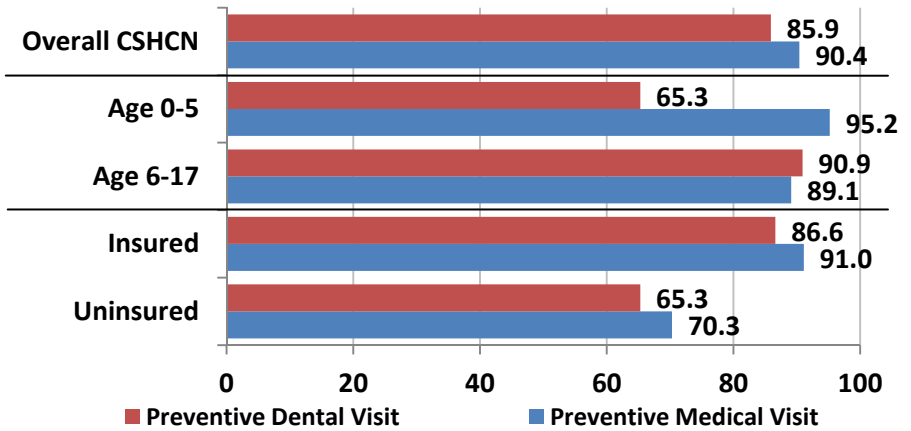
78.6%

All CSHCN

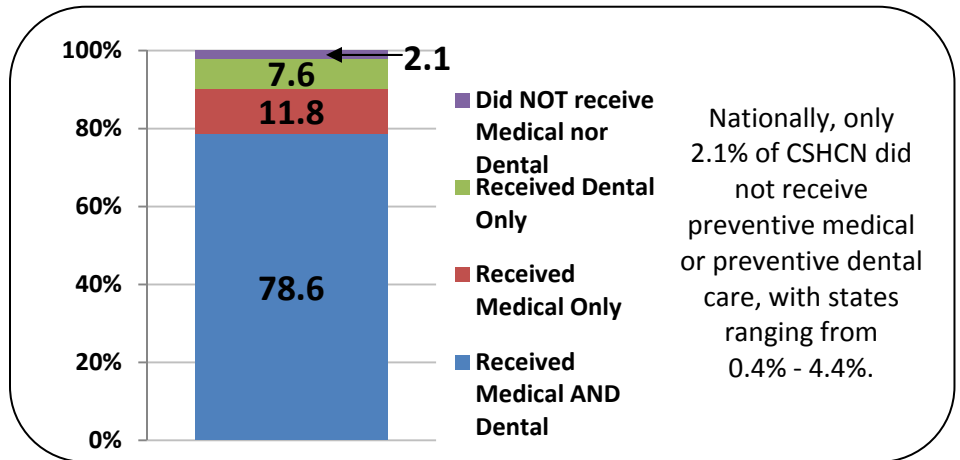
82.1%

Privately insured
CSHCN

Breakdown of Outcome #4: Preventive Medical and Preventive Dental Visits in past 12 months, by Age and Insurance Status



- The prevalence of the preventive dental visit component of Outcome #4 is lower among almost all populations, with less than two-thirds of young CSHCN (age 1-5) receiving dental care.
- Less than two-thirds of uninsured CSHCN receive preventive dental care, with only slightly more receiving preventive dental care.



Trending Across Survey Years: Measurement changed significantly for 2009/10 NS-CSHCN, and therefore cannot be compared to 2001 and 2005/06 NS-CSHCN prevalence rates.

improve health outcomes
 early identification
 avoid missed opportunities
 timely treatment
 identify stressors
 minimize negative impact
 support
 early determinants of lifelong health
 maximize assets
 minimize negative impact
 decrease risk
OUTCOME 4: EARLY AND CONTINUOUS SCREENING
 proper care
 address concerns
 protect future

Using timing as an advantage

Special health care needs arise during different stages of development, from infancy through adolescence. Early and continuous screening allows emerging needs to be identified as early as possible, which is critical to addressing them appropriately and minimizing long term consequences. These ongoing assessments ensure that children receive proper care and support for their existing needs and help prevent secondary conditions. Ongoing assessments also allow each family's strengths to be identified and best utilized. However, many children do not receive this necessary screening. Less than half of CSHCN living below the federal poverty level meet Outcome 4 and CSHCN with public insurance are much less likely to than those with private insurance.

Taking it a Step Further:

The following are questions relating to Outcome #4 that cannot be answered by this national survey data but are important to consider when evaluating how early and continuous screening can best work to improve the health and well-being of CSHCN:

1. Was the child screened for factors related to physical, mental/emotional, and environmental health?
2. Are families included in the screening process and are their concerns addressed during preventive visits?
3. When needs are identified, are proper steps taken for diagnosis, treatment and follow-up?

Outcome #5

Community-based service systems are organized for ease of use

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- Medical Home
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- Transition to Adulthood

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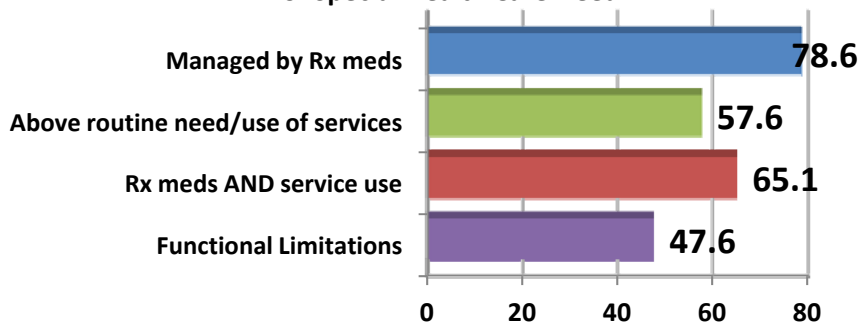
Measurement

For CSHCN to meet Outcome 5, families must have no difficulties or delays in getting services, and be only sometimes or never frustrated in efforts to get services for CSHCN. It is based upon the following 7 questions:

During the past 12 months did you have any difficulties or delays getting services for [child] because...

1. ...[he/she] was not eligible for the services? (C4Q03_A)
2. ...the services [SC] needed were not available in your area? (C4Q03_B)
3. ...there were waiting lists, backlogs, or other problems getting appointments? (C4Q03_C)
4. ...of issues related to cost? (C4Q03_D)
5. ...you had trouble getting the information you needed? (C4Q03_E) *Yes or no*
6. During the past 12 months did you have difficulties or delays for any other reason? (C4Q03_F) *Yes or no*
7. During the past 12 months, how often have you been frustrated in your efforts to get services for [S.C.]? (C4Q04) *Never, sometimes, usually or always*

Prevalence of Ease of Community-Based Service Access by Type of Special Health Care Need



- Access to community-based services differs by CSHCN's type of special health care need. Less than half of CSHCN who have functional limitations meet Outcome #5, compared to over ¾ of CSHCN whose condition is managed by prescription medication.

*Emotional, behavioral or developmental

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30.5%
Uninsured
CSHCN

49.7%
CSHCN with one or
more EBD* issues

56.4%
CSHCN with more
complex needs

65.1%
All CSHCN

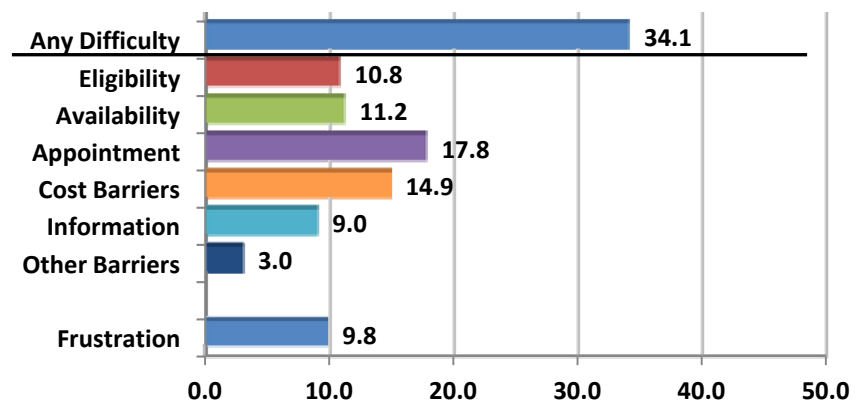
71.8%
Privately insured
CSHCN



Structural support for optimal outcomes.
 CSHCN have complicated needs that are usually not isolated to a single doctor's office. CSHCN and their families often require services from multiple providers as well as schools and other community based organizations. Services must be organized in a way that reduces frustration; otherwise the barriers to access will leave children without needed services. Integrated and accessible services allow CSHCN and families to connect with the resources they need to grow and develop optimally.

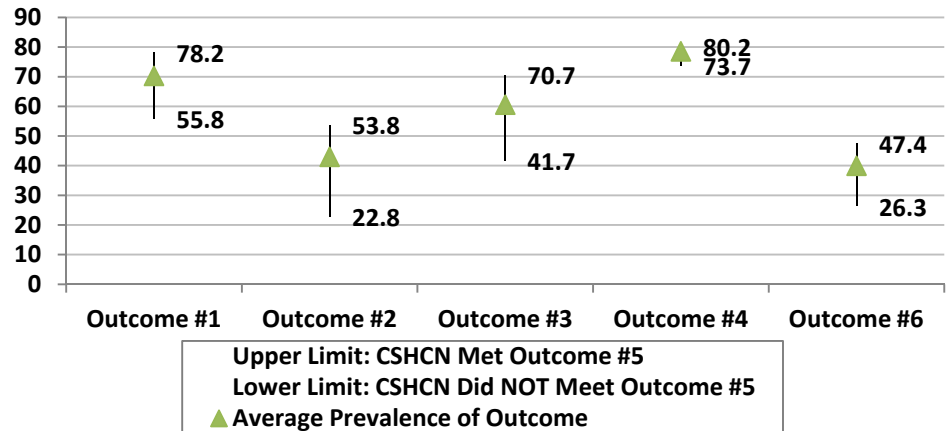
Trending Across Survey Years:
 Measurement changed significantly for 2009/10 NS-CSHCN, and therefore cannot be compared to 2001 and 2005/06 NS-CSHCN prevalence rates.

Prevalence of Specific Difficulties and Parental Frustration in Accessing Community-Based Services



- CSHCN were most likely to experience difficulty with waiting lists, backlogs, or other problems getting appointments (17.8%), with slightly lower rates for issues related to costs of care (14.9%).
- Almost 1 in 10 (9.8%) parents of CSHCN experienced frustration in efforts to get services for their CSHCN.

CSHCN who do not experience difficulties in accessing community-based services are more likely to meet all other MCHB Core Outcomes



- CSHCN who meet this outcome are over twice as likely to meet criteria for a medical home (53.8% vs 22.8%) and significantly more likely to report having adequate insurance (70.7% vs 41.7%), revealing the interconnected nature of the MCHB Core Outcomes

Taking it a Step Further:

The following are questions relating to Outcome #5 that cannot be answered by this national survey data but are important to consider when evaluating how early and continuous screening can best work to improve the health and well-being of CSHCN:

- Do families know about all community-based services available?
 - How is information about these available services disseminated?
- Are communities properly structured to offer these types of services?
 - What infrastructure supports are needed to facilitate integrated systems?

Outcome #6

CSHCN youth receive services needed for transition to adulthood

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, families of CSHCN can easily navigate such a system, leading to positive experiences seeking care and interacting with service providers. Advancing integrated care systems for CSHCN and their families is a national mandate under Public Law 101-239 as well as 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 determine progress toward an integrated system of care for all CSHCN, the Federal Maternal and Child Health Bureau established the following six core outcomes:

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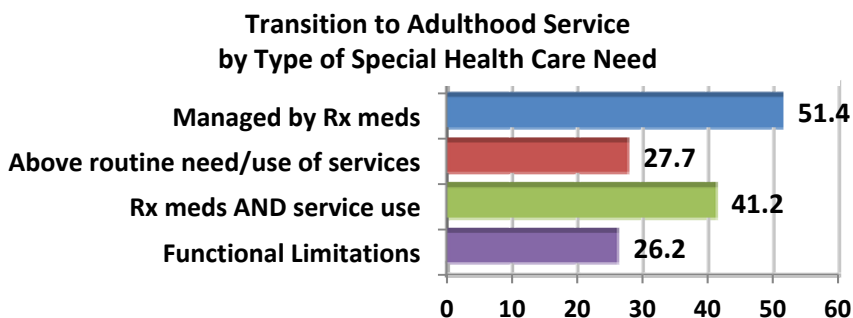
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Measurement

For CSHCN to meet Outcome 6, the following criteria must be met (CSHCN age 12-17 years only):

1. The youth's doctor has discussed each of the following 3 topics with him/her (or parent indicated that such discussions were not needed):
 - Transitioning to doctors who treat adults (C6Q0A_B)
 - Changing health needs as youth becomes an adult (C6Q0A)
 - How to maintain health insurance as an adult (C6Q0A_E)
2. Doctor usually or always encourages the youth to take age-appropriate responsibility for managing his or her own health needs (C6Q08)

This measure has been endorsed by the National Quality Forum (NQF)



- CSHCN whose condition is solely managed by prescription medication or in combination with above need/use of services are more likely to meet transition to adulthood criteria.
- CSHCN with functional limitations are least likely to meet transition to adulthood criteria.

*Emotional, behavioral or developmental (EBD) issues

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

19.6%

Uninsured
CSHCN

28.9%

CSHCN with one or
more EBD* issues

32.5%

CSHCN with more
complex needs

40.0%

All CSHCN

50.2%

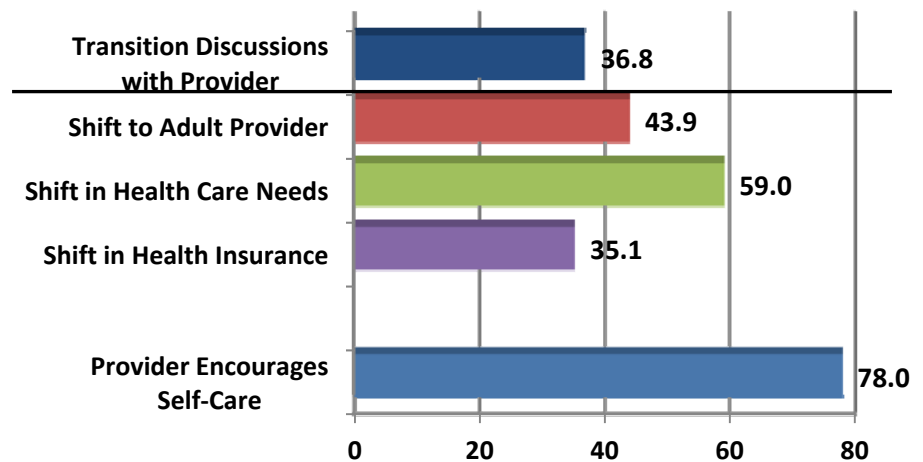
Privately insured
CSHCN

continuity through stages
 support during critical periods
resilience
 lasting effects
 personalization
 decision-making
 discussion and planning
 lifelong health
 face challenges independence
OUTCOME 6: TRANSITION TO ADULT CARE
 reduce stress
 no gaps in care
 involvement
 self care skills

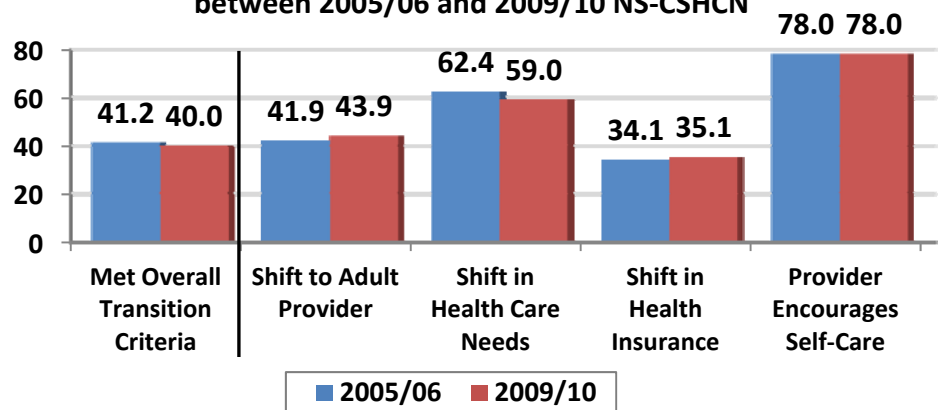
Providing the ingredients for resiliency through change.

The transition to adulthood is a critical developmental period during which youth undergo extra stress and are particularly vulnerable. The way critical periods are managed can lead to different stress response patterns and different functional trajectories. Proper support during transitions is crucial for preventing long term negative consequences. CSHCN benefit from continuity of care and support as they progressively assume more responsibility for their health needs. Children who do not receive transition services are more likely to have unmet health needs as adults. The importance of this outcome is clear, yet it is the one that CSHCN are least likely to meet.

Prevalence of Specific Transition Discussions with Provider and Encouragement of Self-Care



Shifts in Prevalence of Transition to Adulthood Discussions between 2005/06 and 2009/10 NS-CSHCN



- CSHCN are most likely to receive encouragement to take age-appropriate responsibility for managing his or her own health needs (78.0%).
- However, less than half of CSHCN (age 12-17 years) have had discussions regarding transition issues with their provider, with lowest rates for discussions on shift in health insurance and shift to adult health care provider.

Taking it a Step Further:

The following are questions relating to Outcome #6 that cannot be answered by this national survey data but are important to consider when evaluating how transition to adulthood can assist in improving the health and well-being of CSHCN into early adulthood:

- Was the transition to adulthood successful? How would we measure that success?
- What transition and self-care planning occurred earlier in life to prepare for transition?
- In what areas are youth taking appropriate responsibility for their own well-being with regard to nutrition, exercise, social role, self-support and reproductive future?