Only 1 of every 4

Maine adolescents with special health care needs (SHCN), ages 12-17, received the services needed to make transitions to adult health care (28%).

There are not sufficient data to look at Maine disparities or trends. Nationwide, 12-17 year olds with SHCN were more likely to receive transition services if their parents were born in the US or if the family demonstrated resilience.

Among Maine’s 12-17 year olds with SHCN:

• **63.6%** had a chance to speak with their health care provider privately (without an adult in the room) at their last preventive check-up.

• **73.2%** had a health care provider who their parents knew actively worked with the adolescent to gain skills to manage their health and health care.

• **28.6%** had a health care provider who their parents knew actively worked with the adolescent to understand the changes in health care that occur at age 18.

• **15.6%** had a doctor who discussed the shift to providers who treat adults, if such a shift was needed.

• **86.3%** had a health care provider who their parents knew actively worked with the adolescent to make positive choices about their health.

National Performance Measures – Children with Special Health Care Needs

• **NPM 11**: Percent of children with and without special health care needs, ages 0 through 17, who have a medical home

• **NPM 12**: Percent of adolescents with and without special health care needs, ages 12 through 17, who received services necessary to make transitions to adult health care

• **NPM 15**: Percent of children, ages 0 through 17, who are continuously and adequately insured

Stakeholder Input

Challenges that impact transition include:

• Shortage of providers who understand certain conditions (e.g., ASD)

• Lack of communication across siloed systems

Strategies that could improve transition include:

• Training for young adults on managing care and self-advocacy

• Provider training

• Identify providers for adults

• Increase services to support transition to adult care

• Insurance coverage for case management for adults

• MaineCare as wraparound for under-insured

Only 11.2% had an up-to-date written plan for meeting specific health goals and needs.

47.6% lived with parents who knew or had discussed with someone how to obtain or keep some type of health insurance coverage as their adolescent becomes an adult.
Maine children with special health care needs (CSHCN) who needed care coordination received effective care coordination (63%). CSHCN with more complex health needs were less likely to receive effective care coordination than were CSHCN with less complex health needs.

Sufficient data are not available to look at care coordination trends in Maine. Additionally, the survey’s web query tool does not allow users to look for disparities in care coordination among CSHCN in Maine or nationwide.

Care coordination related measures among Maine’s CSHCN show that:

- **31.9%** had health care providers who **communicated** with the child’s school, special education program, or child care provider.
- Among those children whose parents needed help arranging or coordinating the child’s care among different services or doctors the child uses, only **23.0%** got that help.

**48%** of CSHN in Maine received **coordinated, ongoing, comprehensive care within a medical home.**

- **18.4%** received care in a **well-functioning system** (family partnership, medical home, early screening, adequate insurance, easy access to services, and preparation for adult transition).

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**National Performance Measures – Children with Special Health Care Needs**

NPM 11: Percent of children with and without special health care needs, ages 0 through 17, who have a medical home

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Maine Children with Special Health Care Needs: Access to Care
Maternal and Child Health Block Grant Data Brief

<table>
<thead>
<tr>
<th>Domain Listening</th>
<th>Regional Forums</th>
<th>Survey: Professionals</th>
<th>Survey: Non-professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score: 4 (rank: 4)</td>
<td>Top 2: 1 of 2 forums</td>
<td>26% adequate insurance (rank=3); 7% access to specialty care; 11% access to medical home; 26% availability of mental health services (rank=4)</td>
<td>31% adequate insurance (rank=2); 17% access to specialty care; 8% access to medical home; 15% availability of mental health services</td>
</tr>
</tbody>
</table>

48% of Maine children with special health care needs (CSHCN) have a medical home. Children with more complex care needs are less likely to have a medical home than were children with less complex care needs.

There are not sufficient data to look at Maine disparities or trends. Nationwide, CSHCN are more likely to have a medical home if they have adequate insurance and were continuously insured in the past year; have only private health insurance; have a household income 400% of the federal poverty level or higher; or have a household member with a college degree or higher.

Among Maine CSHCN:

- **93.0%** had a preventive check-up in the past 12 months.
- **89.7%** of 1-17 year olds had a preventive dental visit in the past 12 months.
- **87.6%** have a personal doctor or nurse.
- **86.8%** have a usual source for sick care.
- **85.8%** receive family-centered care.
- **15.0%** did not receive needed health care at some point during the past 12 months.

- **38.8%** had inadequate current insurance and/or a gap in insurance coverage during the past year.
- **25.2%** live in families that had problems paying some of the child’s medical bills in the past 12 months.
- **37.6%** live in families that paid $500 or more in out-of-pocket costs for the child’s health care in the past 12 months.

**National Performance Measures – Children with Special Health Care Needs**

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**Stakeholder Input**

**Challenges** that impact access to care include:

- Medical home is limited under MaineCare
- Inconsistent definition of medical home and lack of understanding
- Services are difficult to access
- Wait lists
- Lack of providers, interpreters for the deaf, and early interventionists
- Lack of communication across siloed systems

**Strategies** that could improve access to care include:

- Improved access to medical home
- Pediatric home model
- Family navigators
- Care coordination
- Provider awareness and training
- More providers in rural areas; support for critical access hospitals
- Increase MaineCare rates
- Make telehealth billable
- Simpler payment systems

Maine children with special health care needs (CSHCN) live with parents who often felt aggravation from parenting during the past month.

Parents of CSHCN with more complex health needs were more likely to often feel aggravation from parenting than were parents of CSHCN with less complex health needs. (Note: Parental aggravation is the survey’s term for parental stress.)

Sufficient data are not available to look at parental aggravation trends in Maine. Additionally, the survey’s web query tool does not allow users to look for disparities in parental aggravation among CSHCN in Maine or nationwide.

Among Maine’s CSHCN:

- **17.0%** lived with parents who always or usually felt the child was much harder to care for than most children his or her age.
- **17.1%** lived with mothers and **11.2%** lived with fathers, whose mental and emotional health was fair or poor.
- **13.6%** had family members who stopped working or cut back on hours worked because of the child’s health or health conditions.

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