

Maine Children with Special Health Care Needs: Transition

Maternal and Child Health Block Grant Data Brief

Domain Listening	Regional Forums	Survey: Professionals (n=401)	Survey: Non-professionals (n=909)
Rank: 3 Score: 14	Top 2: 1 of 2 forums	36% (rank=1)	36% (rank=1)

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**.

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
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- 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**.

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



Source: Child and Adolescent Health Measurement Initiative. 2016-2017 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Retrieved 12/17/2019 from www.childhealthdata.org.

Maine Children with Special Health Care Needs: Care Coordination

Maternal and Child Health Block Grant Data Brief

Domain
Listening

Regional
Forums

Survey:
Professionals

Survey:
Non-professionals

Rank: 3 Score: 14

Top 2: 2 out of 2 forums

Selected by 26%

Selected by: NA

2 of every 3

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.

Stakeholder Input

Challenges that impact care coordination include:

- Parents often are the care coordinators and are overwhelmed
- Over-reliance on MaineCare
- Lack of communication across siloed systems

Strategies that could **improve** care coordination include:

- Shared medical records across providers
- Family navigators in primary care offices
- Tele-navigator services
- Help Me Grow model
- Pay for care coordination
- Blend funding sources; lessen reliance on MaineCare

- **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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Maine Children with Special Health Care Needs: Access to Care

Maternal and Child Health Block Grant Data Brief

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

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.

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

- **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.

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Maine Children with Special Health Care Needs: Caregiver Stress

Maternal and Child Health Block Grant Data Brief

Domain Listening	Regional Forums	Survey: Professionals (n=401)	Survey: Non-professionals (n=909)
Score: NA	Top 2: 0 of 2 forums	31% (rank=2)	23% (rank=5)

1 in 5

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.

Stakeholder Input

Challenges that increase caregiver stress include:

- Parents and families are acting as care coordinators and are overwhelmed
- Shortage of providers who understand certain conditions (e.g., ASD)
- Lack of understanding of medical home by families

Strategies that could lessen caregiver stress include:

- Family guides / navigators
- Support and resource groups
- Peer networks
- Warm line
- Parent advocates
- Parent education

- **63.1%** of those who needed care coordination received **effective care coordination**.
- **86.6%** lived with parents who had **someone they could turn to for day-to-day emotional support** with parenting or raising children.
- **52.2%** lived with parents who thought they were **coping very well** with the day-to-day demands of raising children.
- **84.2%** were in families that, all or most of the time, **stayed hopeful** even in difficult times.

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