

Region (to be completed by project staff): _____

Integrated Community Systems for Children and Youth with Special Health Care Needs in Maine



Regional Report Card for FAMILY MEMBERS

County of Residence: _____ Town (optional): _____

My child/children with special health care needs/disabilities is/are between the ages of:

birth-2 _____ 3-5 _____ 6-10 _____ 11-14 _____ 15-17 _____ 18-20 _____ 21-25 _____

Legend: A = Excellent/Very Satisfied
 B = Good/Fairly Satisfied
 C = Fair/Satisfied
 D = Poor/Not Satisfied
 N/A = Not applicable

Please check just one “grade” for each indicator using an X or check mark. If the indicator doesn’t relate to you, please check N/A. If you are uncertain, leave it blank. If the box is shaded no response is needed there.

| Indicators: | A | B | C | D | N/A |
|---|---|---|---|---|-----|
| <i>Performance Measure #1: Youth with special health care needs and their families will partner in decision making at all levels, and will be satisfied with the services they receive.</i> | | | | | |
| Indicator 1.1: Quality of the regular or “primary” health care your child/children receive. | | | | | |
| Indicator 1.2: Access to referrals and appointments for additional services he/she may need. | | | | | |
| Indicator 1.3: Coordination between your child’s/children’s regular doctor and any specialty doctors/providers you may see. | | | | | |
| Indicator 1.4: Level of your involvement/input in decision making relative to your child/children’s plan of care. | | | | | |
| Indicator 1.5: Understanding the steps you can take when you are not satisfied with the services you receive on behalf of your child/children. | | | | | |

| Indicators: | A | B | C | D | N/A |
|---|---|---|---|---|-----|
| Indicator 1.6: You get paid if you are involved in policy making at the state/local level as a family leader. | | | | | |
| Indicator 1.7: You are active in policymaking at the state and local levels as a family leader. | | | | | |
| | | | | | |
| <i>Performance Measure #2: All children/youth with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home (a doctor's office where all your child's/children's medical care is received or coordinated).</i> | | | | | |
| Indicator 2.1: Your child's/children's regular source of medical care is provided through a pediatrician or family doctor (also known as a primary care provider [PCP]). | | | | | |
| Indicator 2.2: Your child's/children's doctors and their staff communicate in a way that is clear, understandable and culturally sensitive to you and your family. | | | | | |
| Indicator 2.3: Your child's/children's source of regular medical care identifies, discusses, and addresses his/her comprehensive needs. | | | | | |
| Indicator 2.4: Your child's/children's regular source of primary medical care coordinates well-child checks, such as: | | | | | |
| Vision | | | | | |
| Hearing | | | | | |
| Developmental Services | | | | | |
| Behavioral/Mental Health Services | | | | | |
| Oral Health | | | | | |
| Immunizations | | | | | |
| Newborn Screening | | | | | |

| Indicators: | A | B | C | D | N/A |
|---|---|---|---|---|-----|
| Indicator 2.5: Referrals to needed services are taken care of by your regular provider/doctor. | | | | | |
| | | | | | |
| Performance Measure #3: All youth and their families will have adequate private and/or public insurance to pay for the services they need. | | | | | |
| Indicator 3.1: Your health insurance covers the costs of needed services for your child/children, such as: | | | | | |
| Mental Health | | | | | |
| Dental Care | | | | | |
| Age Appropriate Well-Child Checks | | | | | |
| Durable Medical Equipment | | | | | |
| Ancillary (other) Services | | | | | |
| Non-Durable Medical Supplies | | | | | |
| Care Coordination | | | | | |
| Prescriptions | | | | | |
| Specialty Care | | | | | |
| Related Therapies (PT, OT, Speech) | | | | | |
| In Home Nursing | | | | | |
| Other (please identify): | | | | | |

| Indicators: | A | B | C | D | N/A |
|---|---|---|---|---|-----|
| Indicator 3.2: The out-of-pocket costs (costs that are not covered by insurance) to your family are (circle one from the list below): | | | | | |
| Reasonable Affordable Don't Know Not applicable | | | | | |
| Indicator 3.3: You and your family get to choose the providers you use (rather than the insurance company). | | | | | |
| Indicator 3.4: Your insurance provides (circle all that apply): | | | | | |
| Timely approval for needed care Overall parental satisfaction Overall child/youth satisfaction Clear information about coverage and resources Complaint procedures to providers and families/youth if you are not happy with what they have covered | | | | | |
| | | | | | |
| <i>Performance Measure #4: All children and youth will be screened early and continuously for special health care needs.</i> | | | | | |
| Indicator 4.1: Prenatal screening begins in the first trimester of pregnancy, e.g., substance abuse, genetics. | | | | | |
| Indicator 4.2: Infants, children and youth are monitored for special health care needs and developmental delays. | | | | | |
| Indicator 4.3: Your child/children receive(s) age-appropriate well-child checks such as: | | | | | |
| Vision | | | | | |
| Hearing | | | | | |
| Developmental Needs | | | | | |
| Behavioral/Mental Health | | | | | |
| Oral Health | | | | | |
| Metabolic | | | | | |

| Indicators: | A | B | C | D | N/A |
|--|---|---|---|---|-----|
| Indicator 4.4: Your child/children receive(s) needed follow-up if the screening identifies problems: | | | | | |
| Vision | | | | | |
| Hearing | | | | | |
| Developmental | | | | | |
| Behavioral | | | | | |
| Mental Health | | | | | |
| Oral Health | | | | | |
| Metabolic | | | | | |
| | | | | | |
| <i>Performance Measure #5: Community-based services will be organized in ways that youth and their families can use them easily.</i> | | | | | |
| Indicator 5.1: Your child/children has/have a written health care plan that coordinates providers and services. | | | | | |
| Indicator 5.2: You know who is the lead coordinator for the plan of care. | | | | | |
| Indicator 5.3: You are able to access a full range of services that meet the needs of your child/children. | | | | | |
| Indicator 5.4: Specialty care is available within a reasonable distance (you don't have to drive too far). | | | | | |
| | | | | | |
| <i>Performance Measure #6: All youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence.</i> | | | | | |
| Indicator 6.1: Your child/children has/have a transition plan beginning by age 14 that addresses his/her needs in the following areas: | | | | | |

| Indicators: | A | B | C | D | N/A |
|--|---|---|---|---|-----|
| School and Educational Goals | | | | | |
| Goals for College and Further Education | | | | | |
| Employment | | | | | |
| Staying Healthy | | | | | |
| Insurance | | | | | |
| Community Living | | | | | |
| Driving/Transportation | | | | | |
| Assistive Technology | | | | | |
| Necessary Accommodations | | | | | |
| Other (please specify): | | | | | |
| Indicator 6.2: Your child/children (age 14 or older) has/have a transition plan that was written with input from: | | | | | |
| You | | | | | |
| Your Family Members | | | | | |
| Your Teachers | | | | | |
| Your Doctor(s) or Other Health Care Providers | | | | | |
| Vocational Rehabilitation | | | | | |
| Other Appropriate Agencies | | | | | |

| Indicators: | A | B | C | D | N/A |
|--|---|---|---|---|-----|
| Other (please specify): | | | | | |
| Indicator 6.3: If your regular doctor is a pediatrician, he/she is helping your child/children transition to an adult doctor or family doctor. | | | | | |
| Indicator 6.4: You are satisfied with the information you have available to make informed decisions about your child's/children's health care and other services. | | | | | |
| Indicator 6.5: You and your family have received the necessary services/supports (at high school graduation or no later than age 21) to transition successfully to: | | | | | |
| College or Other Further Education | | | | | |
| Related to Financial Aid Information | | | | | |
| Employment | | | | | |
| Health Insurance | | | | | |
| Driving/Transportation | | | | | |
| Community Living/Housing | | | | | |
| Personal Supports | | | | | |
| Social Security Work Incentives (e.g., PASS, 1619 a and b) | | | | | |
| Other (please identify): | | | | | |

Additional Comments:

Suggestions for Improvement:

THANK YOU!

Please return this to your Regional Youth Facilitator, or mail to:

Debbie Gilmer
Maine Support Network
PO Box 390
Readfield, ME 04355

www.servicesforme.org