Who are Children with Special Healthcare Needs?

The Maternal and Child Health Bureau (MCHB) defines Children with Special Healthcare Needs (CSHCN) as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” This includes a diverse group of children younger than 18 (about 20% of children in Rhode Island). It includes children with chronic conditions, children with more medically complex health issues, and children with behavioral or emotional conditions. These children may have physical, developmental, behavioral, or emotional healthcare needs. These needs may appear in children of any age. CSHCN are often diagnosed with more than one condition. They also frequently experience difficulties in several areas, such as learning, behavior, gross or fine motor skills, chronic pain, and making and keeping friends. The Rhode Island Department of Health (RIDOH) strives to ensure that all children with special healthcare needs receive timely, high-quality, culturally sensitive healthcare.

About the Data

Throughout this brief, data are presented as they were originally collected and reported for age, race, and ethnicity. RIDOH recognizes that these categories may not reflect how people and communities define themselves. We acknowledge these limits and strive to use language that is welcoming and inclusive of every Rhode Islander whenever possible.

Demographics

Rhode Island Population | 1,059,639
Total CSHCN (age <17) | 41,977

This section provides data on Rhode Island CSHCN during 2017. The age range for each category appears in parentheses. (For example, race/ethnicity data are available for Rhode Island CSHCN age <17.)

Figure 1
Race/Ethnicity of Children with Special Healthcare Needs in Rhode Island (age <17)

Source: National Survey of Children’s Health, 2017-2018
NOTES: While these data were originally collected using the terms Hispanic and Non-Hispanic, this report uses the term Hispanic/Latinx as a more inclusive alternative to Hispanic, Latino, or Latina.

Twenty-seven percent (27%) of CSHCN age <17 are Hispanic/Latinx.
Based on the Most Recent Data Available for Rhode Island

35% of Rhode Island families with CSHCN reported living below the federal poverty level during the past 12 months.

In 2017, more than a third (35%) of Rhode Island families with CSHCN reported living below the federal poverty level during the past 12 months.

In 2017, 96% of CSHCN younger than 19 had health insurance coverage.

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Rhode Island Children with Special Healthcare Needs (CSHCN) versus US CSHCN

<table>
<thead>
<tr>
<th>National Measure</th>
<th>How Does Rhode Island Compare to the Country as a Whole?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent of CSHCN who have a medical home(^1,2)</td>
<td>42.5% vs 43.3% 2017</td>
</tr>
<tr>
<td>Percent of CSHCN who received services necessary to make transitions to adult care(^2)</td>
<td>16.5% vs 17.0% 2017</td>
</tr>
<tr>
<td>Percent of children with special healthcare needs(^2)</td>
<td>20.5% vs 18.2% 2017</td>
</tr>
<tr>
<td>Percent of CSHCN who received care in a well-functioning system(^2)</td>
<td>15.1% vs 14.8% 2017</td>
</tr>
</tbody>
</table>

KEY FACTS

Based on the Most Recent Data Available for Rhode Island

1 in 3 families with CSHCN report not receiving needed care coordination.\(^2\)

Among children age 3-17, 2.7% have Autism, Asperger syndrome, or other Autism Spectrum Disorder.\(^2\)

1 in 4 high school students with special healthcare needs report attempting suicide.\(^3\)

7 in 10 CSHCN have “more complex” healthcare needs.\(^2\)

Fewer Rhode Island families with CSHCN have problems paying for the child’s medical or healthcare bills, compared to US families with CSHCN.\(^2\)
This section provides data on health inequities. Health inequities are systemic, avoidable, unfair, and unjust differences in health status across population groups.

RIDOH recognizes that the conditions in which people are born, grow, live, learn, work, and play affect health in powerful ways. Public health research and data show that many adverse health outcomes have resulted from generations-long social, economic, and environmental inequities. These inequities include poverty, discrimination, racism, and their consequences. For example, segregation in housing and education and racist mortgage lending and zoning policies have affected communities differently and have had a greater influence on health outcomes than genetics, individual choices, or access to healthcare.

Removing obstacles to health and improving access to good jobs with fair pay, quality education and housing, safe environments, and healthcare can help reduce health inequities and improve opportunities for every Rhode Islander.

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**Footnotes**

1. A medical home is an approach to providing comprehensive primary care that facilitates partnerships among individual patients, their primary or specialty providers, and, when appropriate, the patient’s family.

2. National Survey of Children’s Health (NSCH)

3. Rhode Island Youth Risk Behavior Survey (YRBS)

4. Children in this group have elevated needs or functional limitations or require use of specialized services and therapies. These children rely on one or more of a wide array of services to manage their chronic health conditions.

RIDOH would like to acknowledge the contributions of **SISTA Fire** for providing their time and feedback on the content and development of this publication. SISTA Fire is a small and growing network of women of color from across Rhode Island who are on a journey to create a space where they can build foundations for deep solidarity across differences, strengthen community connections, and create change in their lives and communities.
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