

# Children with Special Needs

## DEFINITION

*Children with special needs* are those who have a chronic disease or disability that requires educational services, health care, and/or related services of a type or amount beyond that required generally by children. Special needs can be physical, developmental, behavioral, or emotional. This indicator measures the number of children enrolled in Early Intervention, special education, Supplemental Security Income (SSI) and Medical Assistance for children with special health care needs.

## SIGNIFICANCE

An estimated 20% of children in the U.S. and 21% of children in Rhode Island have at least one special health care need.<sup>1</sup> Children with special health care needs (CSHCN) can have impairments of varying degrees in physical, developmental, emotional, and/or behavioral functioning.<sup>2</sup> Parental reports of developmental screening for young children during health care visits in Rhode Island increased from 15% in 2007 to 32% in 2012.<sup>3</sup> Nationally, 41% of CSHCN have two or more special health needs. Health conditions most commonly reported are Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder, asthma, learning disabilities, speech problems, developmental delay, behavioral problems, anxiety, and depression.<sup>4</sup>

Children with mild or severe disabling conditions have special needs related to physical health, mental health, education, family support, housing, child care, and recreation.<sup>5</sup> Health-related needs are best met via a comprehensive, coordinated, continuous, accessible, and family-centered medical home.<sup>6</sup>

Rhode Island high school students with disabilities reported experiencing physical fights, being electronically bullied, and being bullied at school, as well as acute depression more than their non-disabled peers. They also reported higher rates of mental health problems, physical inactivity, poor grades, sexual activity, forced sexual intercourse, cigarette smoking, drinking, and using marijuana.<sup>7,8</sup>

CSHCN may require medical services, equipment, assistive technology, or home modifications that may result in serious financial burdens on families.<sup>9,10</sup> Having children with special needs significantly impacts parents' finances, employment, and family lives.<sup>11,12</sup> In 2015, the Rhode Island General Assembly established Achieving a Better Life Experience (ABLE) tax-free saving accounts for people who become disabled before age 26, which cover a range of expenses, including health care, education, housing, transportation, and employment training.<sup>13,14,15</sup>

## Children Enrolled in Early Intervention

- ◆ States are required by the federal *Individuals with Disabilities Education Act (IDEA) Part C* to identify and provide appropriate Early Intervention services to all infants and toddlers under age three who have developmental delays or have a diagnosed physical or mental condition that is associated with a developmental delay.<sup>16</sup>
- ◆ In Rhode Island in 2016, nine certified Early Intervention (EI) provider agencies served 4,186 children. As of June 30, 2016, there were 2,022 children enrolled in EI (6% of all children under age three). Nearly two-thirds (62%) of those children receiving EI services were male and just over one-third (38%) were female. EI enrollment was not evenly distributed among children by age, with 32% less than one year old, 50% between ages one and two, and 19% between ages two and three during that time period.<sup>17</sup>

## Children Enrolled in Special Education

- ◆ Under *IDEA Part B*, local school systems are responsible for identifying, evaluating, and serving students ages three to 21 who have disabilities that might require special education and related services.<sup>18</sup>
- ◆ As of June 30, 2016 in Rhode Island, there were 3,050 children ages three to five who received preschool special education services.<sup>19</sup>
- ◆ In Rhode Island as of June 30, 2016, 19,953 students in public schools ages six to 21 received special education services (14% of all students). Thirty-eight percent of students receiving special education services in Rhode Island had a learning disability.<sup>20</sup>
- ◆ Early Intervention (EI) programs are required to provide transition services for children who are enrolled in EI and who may be eligible for special education services at age three. In 2016, 63% of the 952 children who reached age three while in EI were determined to be eligible for preschool special education, 20% were found not eligible, and 14% did not have eligibility determined when exiting EI. The remainder completed their service plan prior to reaching the maximum age for EI, moved out of state, withdrew, or were otherwise unreachable for follow-up.<sup>21</sup>

## Medical Assistance for Children With Special Health Care Needs

- ◆ As of December 31, 2016, there were 4,961 Rhode Island children and youth under age 19 receiving Medical Assistance benefits through their enrollment in the federal Supplemental Security Income (SSI) program.<sup>22,23</sup>
- ◆ In Rhode Island, the Katie Beckett eligibility provision provides Medical Assistance coverage to children under age 19 who have serious disabling conditions, in order to enable them to be cared for at home instead of in an institution.<sup>24</sup> As of December 31, 2016, there were 961\* Rhode Island children enrolled through the Katie Beckett provision, a decline of 46% from the peak enrollment of 1,770 in 2007.<sup>25,26</sup>
- ◆ Children with special health care needs have a variety of coverage options under Medicaid. Medicaid coverage also provides access to the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit, which requires that children receive all of the services they need, either as a direct benefit or wrap-around benefit to commercial coverage they might have.<sup>27,28</sup>

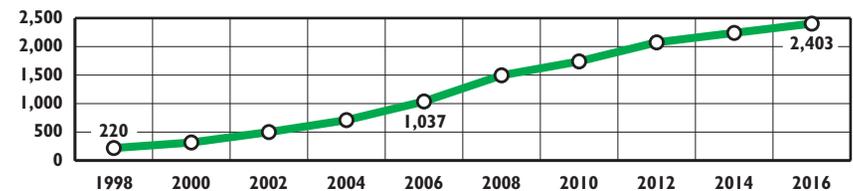
## Children With Special Needs in the Child Welfare System

- ◆ Children and youth who are in the child welfare system are more likely to have special needs, including behavioral and emotional problems, developmental delays, and serious health problems than other children. They often enter the child welfare system in poor health and face difficulties accessing services while in care.<sup>29,30</sup>
- ◆ As of December 31, 2016, 2,019\* children in Rhode Island were enrolled in Medical Assistance through the child welfare system.<sup>31</sup> Per provisions of the federal *Affordable Care Act (ACA)*, all youth who turned age 18 while in foster care are eligible for Medicaid coverage until they reach age 26 in the state in which they aged out of care.<sup>32,33</sup> In Rhode Island, estimates show that 61%\* of all eligible former foster youth were enrolled in Medicaid coverage as of December 31, 2016, up from 59% in 2015.<sup>34</sup>
- ◆ Children who are adopted 2,675\* through the Rhode Island Department of Children, Youth and Families and have special needs may qualify for Medical Assistance coverage. As of December 31, 2016, children were enrolled in Medical Assistance because of special needs adoptions.<sup>35</sup>

## Children With Autism Spectrum Disorder (ASD)

- ◆ Autism Spectrum Disorder (ASD) is a developmental disability that can cause significant social, communication, and behavioral challenges. Children diagnosed with ASD have a variety of symptoms and experience challenges and abilities that range widely in severity. Many children with ASD face challenges in social interaction, speech/language, and communication and demonstrate repetitive behaviors and routines.<sup>36,37</sup>
- ◆ The national ASD prevalence (including mild to severe disorders) among children age eight is estimated to be 14.6 per 1,000 children age eight, or one out of every 68. ASD prevalence is significantly higher among non-Hispanic White children (15.5 per 1,000 children age eight) than non-Hispanic Black (13.2) children and Hispanic (10.1) children, and higher among boys (23.6, or one in 42 boys) than girls (5.3, or one in 189 girls).<sup>38</sup>

## Children Ages Three to 21 With Autism Spectrum Disorder (ASD), Rhode Island, December 1998 – June 2016



Source: Rhode Island Department of Education, Office of Student, Community and Academic Supports, December 1998-June 2016. All data prior to 2000 is a December point in time run, and all data starting in 2000 and beyond is a June point in time run. Numbers include parentally placed students.

- ◆ In June 2016, there were 2,403 Rhode Island children ages three to 21 with ASD who received special education services.<sup>39</sup> The increase in number of children with ASD has been attributed, in part, to improved awareness and better screening and evaluation tools, as well as the broadening of the definition of ASD.<sup>40,41</sup> Early and appropriate identification and sustained interventions by skilled professionals can result in improvements in the levels of independent functioning of children and youth with ASD and long-term life outcomes.<sup>42,43</sup>

### Methodology & References

\*Data for 2016 should be interpreted with caution. In September 2016, the state of Rhode Island instituted a new integrated eligibility determination system (Unified Health Infrastructure Project/UHIP), which may have affected data counts for Rte Care, Rte Smiles, Katie Beckett, former foster youth, and special needs adoptions.

References are on page 179.