

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 those required generally by children. Special needs can be physical, developmental, behavioral, and/or emotional. This indicator measures the number of children with special health care needs enrolled in Early Intervention, special education, Supplemental Security Income (SSI), and Medical Assistance.

SIGNIFICANCE

An estimated 20% of children in the U.S. and 22% of children in Rhode Island have at least one special health care need.¹ Children with special health care needs (CSHCN) can have impairments of varying degrees in physical, developmental, emotional, and/or behavioral functioning.² In 2021, 46% of parents with young children in Rhode Island and 35% of parents nationally reported completing a developmental screening.³ In Rhode Island, 15% of CSHCN have “more complex health needs”, which is the same nationally. Needs among CSHCN can include physical challenges, chronic health conditions, learning challenges, and emotional or developmental issues.⁴ The COVID-19 pandemic disproportionately affected children

with special needs including an increased risk of severe illness, disruptions in necessary services, loss of in-person instruction, and barriers to effective remote learning.⁵

Raising a child with special health care needs is often challenging; however, many parents report caring for a CSHCN can increase patience, compassion, personal strength, and deepen relationships with family and professionals. CSHCN can be a positive influence on other children and adults.⁶

CSHCN may require physical health, mental health, and education services, special equipment, or assistive technology. Health-related needs are best met with a comprehensive, coordinated, and family-centered medical home. Families may also need help with transportation, child care, family support, and home modifications. Having children with special needs can significantly impact parents’ finances, employment, and family lives.^{7,8,9}

In 2014, Congress passed the *Achieving a Better Life Experience Act (ABLE)*, which created tax-exempt saving accounts for people who become disabled before age 26. *ABLE* accounts can cover a range of expenses, including health care, education, housing, transportation, and employment training.^{10,11} In 2015, the Rhode Island General Assembly established *ABLE* savings accounts for Rhode Islanders with special health care needs.¹²



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 (EI) 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.¹³
- ◆ As of June 30, 2022, nine certified EI provider agencies served 1,921 children in Rhode Island. 682 of those children receiving EI services were female and 1,239 were male. Of these children, 55% were white, 31% were Hispanic, 8% were Black, 3% were Multiracial, 2% were Asian, and <1% were American Indian or Alaska Native.¹⁴



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.¹⁵
- ◆ As of June 30, 2022, in Rhode Island, there were 2,920 children ages three to five who received preschool special education services.¹⁶
- ◆ In Rhode Island as of June 2022, 22,165 students in public schools in grades K-12 received special education services (16% of all students). Thirty-six percent of students receiving special education services in Rhode Island had a learning disability.¹⁷
- ◆ 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 2022, 67% of the 1,153 children who reached age three while in EI were determined to be eligible for preschool special education, 16% were found not eligible, and 12% 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.¹⁸



Medical Assistance for Children With Special Health Care Needs

- ◆ As of December 31, 2022, there were 4,392 Rhode Island children and youth under age 19 receiving Medical Assistance benefits through their enrollment in the federal SSI program.^{19,20}
- ◆ In Rhode Island, the Katie Beckett eligibility provision provides Medical Assistance coverage to children under age 19 who have serious disabling conditions, to enable them to be cared for at home instead of in an institution.²¹ As of December 31, 2022, there were 797 Rhode Island children enrolled through the Katie Beckett provision, a decline of 55% from the peak enrollment of 1,770 in 2007.^{22,23}
- ◆ 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 benefit, which requires that children receive all the services they need.^{24,25}



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.^{26,27}
- ◆ As of December 31, 2022, 1,918 children in Rhode Island were enrolled in Medical Assistance through the child welfare system.²⁸ Per provisions of the federal *Affordable Care Act*, 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.²⁹ In Rhode Island, estimates show that 75% of all eligible former foster youth were enrolled in Medicaid coverage as of December 31, 2022.³⁰
- ◆ Children who are adopted through the Rhode Island Department of Children, Youth and Families and have special needs may qualify for Medical Assistance coverage.³¹ As of December 31, 2022, 3,280 children were enrolled in Medical Assistance because of special needs adoptions.³²

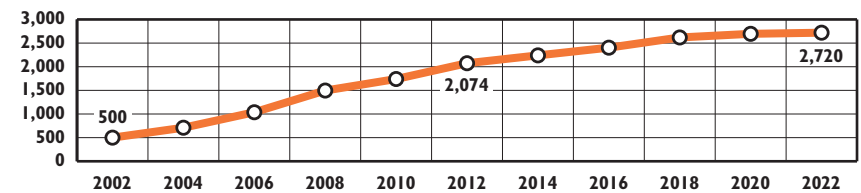


Children With Autism Spectrum Disorder (ASD)

- ◆ 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.³³
- ◆ The national ASD prevalence among children age eight is estimated to be 27.6 per 1,000 children. ASD prevalence is significantly higher among boys (43.0 per 1,000 boys) than girls (11.4 per 1,000 girls). ASD prevalence is higher among Asian/Pacific Islander, Hispanic, and Black children (33.4, 31.6, and 29.3 per 1,000 children, respectively) than non-Hispanic white children (24.3 per 1,000 children).³⁴



Children Ages Three to 21 With Autism Spectrum Disorder (ASD), Rhode Island, June 2002 – June 2022



Source: Rhode Island Department of Education, June 2002– June 2022. Numbers include parentally-placed students.

- ◆ In June 2022, there were 2,720 Rhode Island children ages three to 21 with ASD who received special education services.³⁵ 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.³⁶ 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.^{37,38}

References

¹ Child and Adolescent Health Measurement Initiative. (n.d.). *2020-2021 National Survey of Children's Health: Children with special health care needs*. Retrieved from childhealthdata.org

² Health Resources & Services Administration, Maternal and Child Health Bureau. (2021). *Children and youth with special health care needs*. Retrieved from mchb.hrsa.gov

(continued on page 180)