



Special Health Care Needs/Disabilities

Maternal and Child Health Facts

The Rhode Island Department of Health

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. Children with special needs are a heterogeneous group, varying by the type and severity of the chronic disease or disability. Some chronic and disabling conditions among children include mental retardation, autism spectrum disorders, hearing impairments, communication disorders, seizure disorders and congenital diseases.

Data from the 2005-2006 National Survey of Children with Special Health Care Needs (CSHCN) indicate that Rhode Island's prevalence rate of CSHCN increased from 14.1% to 17.2%. Based on these data, it is now estimated that approximately 41,783 children in Rhode Island have special health care needs. During 2006, Rhode Island had the 2nd highest rate of CSHCN among the 6 New England states and had the 6th highest rates among the 50 states and DC. All of the New England states had higher prevalence rates of CSHCN than the national rate (13.9%).

- Children with special needs often have multiple disabilities. One study found that 34% of children with special needs in Rhode Island had one disability, 34% had two disabilities and 33% had three or more disabilities.

(Source: Rhode Island Department of Health Program Data; 2005-2006 National Survey of Children with Special Health Care Needs)

Access and Utilization



Health Insurance and Usual Source of Care

According to the 2005-2006 National Survey of CSHCN, 6.2% of Rhode Island families with CSHCN reported they had no health insurance for their child compared with 8.8% of CSHCN families in the nation. A lower percentage of Rhode Island families reported their insurance benefits sometimes or never met their child's needs (7.0%) than families in the nation (12.7%). More than one in four (26.8%) families of CSHCN in Rhode Island reported their insurance is inadequate compared to 33.1% of families in the nation.

Medical Home

The needs of children with special needs are best met through a medical home, which can provide care that is comprehensive, coordinated, continuous, accessible and family centered.

Data from the 2005-2006 National Survey of CSHCN indicate that 50.9% of Rhode Island CSHCN received coordinated, ongoing, comprehensive care within a medical home. This reflects a decrease from the figure of 53.9% reported in the 2001 survey of CSHCN.

- Although 90.8% of all children had received a preventive health care visit in the past year, CSHCN were more likely to have had a preventive visit (94.5%) compared to 89.8% of children without special health care needs.
- In Rhode Island, 30.1% families of CSHCN reported they were without family-centered care; 16.6% had doctors who never or sometimes spent enough time with their child; 8.4% had doctors who never or sometimes listen carefully; 15.4% had doctors who never or sometimes provide enough information; and 9.0% had doctors who never or sometimes are sensitive to their family's values.

(Source: Rhode Island Department of Health Program Data; 2005-2006 National Survey of Children with Special Health Care Needs)



Early Intervention (EI)

The number of children, aged birth to three, enrolled in the Rhode Island Early Intervention (EI) Program has continued to rise. During 2008, 3,649 children aged less than three were enrolled in the Rhode Island Early Intervention Program, representing 9.7% of all Rhode Island children aged less than three. This 2008 enrollment figure is a 33% increase from 2003, when 2,746 children were enrolled in the Early Intervention Program. Nearly two-thirds (63%) of children receiving Early Intervention services were male and just over one-third (37%) were female. Enrollment is nearly evenly distributed among children by age, with 30% ages birth to one year, 35% between ages one and two, 33% between ages two and three and 1% over age three.

- Among the 3,649 participants in the Early Intervention Program during 2008, nearly three quarters (74%) had a significant developmental delay, 19% had a single established condition, and 6% had multiple established conditions; no information was available for less than 1%. Children residing in the core cities represented 45% of the total number enrolled in Early Intervention.
- During 2008, 971 children were discharged from the Rhode Island Early Intervention Program upon reaching age three. Of these children, 66% were eligible for preschool special education, 17% were not eligible for preschool special education, and 11% did not have eligibility determined upon exiting the program. The remaining 5% moved out of state, were unreachable or were withdrawn by a parent or guardian.
- In Rhode Island during 2003-2007, 94% of birth defects cases were referred to home visiting programs and 84% of cases with chromosomal anomalies were referred to the Early Intervention Program through the newborn developmental risk screening process. Newborns with birth defects who were not referred to home visiting and/or early intervention via the Newborn Developmental Risk Screening Program were likely referred for services by other referral sources such as the WIC Program or a clinician.

(Source: Rhode Island Department of Health Program Data)



Identification of Babies at Risk: Newborn Developmental Risk Screening

A baby is determined to be at risk if they have any one of the following criteria: a known established condition; birth weight less than 1,500 grams; a neonatal intensive care unit (NICU) hospitalization greater than 48 hours; or the mother is Hepatitis B Surface Antigen (HBsAg) positive. A baby may also be determined to be at risk if they meet at least two of the following criteria: mother's age is less than nineteen or greater than 37; mother's and/or father's education is less than 11th grade; mother is not married; no previous live births; five previous live births; presence of at least one family history risk factor; number of prenatal visits before 36 weeks is less than 6 or total number of prenatal visits is less than 10; no prenatal care visits before the fifth month; gestational age is greater than 37 weeks and birth weight is between 1,500 and 2,500 grams; APGAR scores are less than 7 at one and five minutes.

- Data from the Rhode Island Newborn Developmental Risk Screening Program indicate that the number and percentage of newborns to be at risk for developmental factors decreased slightly from 7,379 (61.4%) in 2007 to 7,082 (60.6%) in 2008—or 6 out of 10 babies born.

Geographic Disparities

- Data from the Newborn Developmental Risk Screening Program indicate that among the 7,082 newborns identified at risk for developmental factors during 2008, 4,271 (60.3%) lived in the core cities. The proportion of babies born at risk is greater among the core cities (76.4%) than the rest of the state (46.1%). The percentage of newborns determined to be at risk varies within the core cities, ranging from 56.4% in West Warwick to 86.1% in Central Falls.

The Rhode Island Pediatric Practice Enhancement Project (PPEP) is serving more families of CSHCN. During 2005, 740 families received assistance from PPEP, and by 2008, this figure quadrupled to 3,209 families in 2008. Based on the estimated 41,783 CSHCN in RI, the percentage served by PPEP rose from 1.8% to 7.7%.

(Source: Rhode Island Department of Health Program Data)

Special Education

The number of children aged 3-21 with disabilities who receive special education services has continued to decrease. During the 2007-2008 academic year, 26,100 students (18%) in kindergarten through the 12th grade were enrolled in special education and another 2,866 preschool children received special education services, resulting in a total of 28,966 children who received special education. This represents a 7.6% decline from the 2005-2006 academic year when 31,362 children received special education.

- Among the 26,100 students who were enrolled in special education during 2007-2008, 10,944 (41.9%) had a learning disability, 4,731 (18.1%) had a speech disorder, 4,460 (17.1%) had a health impairment, 2,723 (10.4%) had an emotional disturbance, 1,271 (4.9%) had autism spectrum disorder, 1,026 (3.9%) had mental retardation, and 875 (3.3%) had some other disability. During 2007-2008, special education students were aged as follows: 38% (5-10), 33% (11-14), 27% (15-18), and 1% (19-21).

(Source: 2009 Rhode Island KIDS COUNT Factbook: Indicator: Children with Special Needs)

Medical Assistance Coverage for Children with Special Health Care Needs

Children and youth who are in the child welfare system are more likely to have special needs when compared to other children. These special needs may include behavioral and emotional problems, developmental delays, and serious health problems such as chronic illnesses and disabilities.

- Children and youth who meet certain disability criteria are eligible for Medicaid and/or cash assistance through the federal Supplemental Security Income (SSI) program. As of December 31, 2008, there were 5,226 Rhode Island children and youth under age 21 receiving Medical Assistance benefits because of their enrollment in SSI.
- As of December 31, 2008, 2,626 children in Rhode Island were enrolled in Medical Assistance due to their foster care status. Rhode Island youth who are in substitute care on their 18th birthday are provided with RIte Care health insurance coverage until their 21st birthday through the Post Foster Care Medical Assistance provision.
- Children who are adopted through the Rhode Island Department of Children, Youth and Families and have special needs may qualify for adoption subsidies, including Medical Assistance. As of December 31, 2008, 2,548 children were enrolled in Medical Assistance because of special needs adoptions.



(Source: Rhode Island Department of Health Program Data)

Impact of Caring for CSHCN on Families

- Data from the 2005-2006 National Survey of CSHCN find nearly half (47.2%) of the Rhode Island families care for their children with special health care needs at home. Many families with CSHCN have had financial problems (14.7%), have had to cut work hours (25.7%) or have had to stop working (10.2%).
- The impact of caring for a child with special health care needs on the family was further analyzed by income and insurance. Families with incomes below 200% of the federal poverty level or without insurance experience a stronger impact on their finances, employment and time than families at/above 200% of the federal poverty level or with insurance.

(Source: Rhode Island Department of Health Program Data; 2005-2006 National Survey of Children with Special Health Care Needs)

Health Status

Disability and Health Risks

According to the 2007 Rhode Island Youth Risk Behavior Survey (YRBS):

- 23% of students identified themselves as having a disability.
- Students with disabilities are more likely to smoke cigarettes, drink alcohol, and use marijuana before the age of 13. They are also more likely to continue these risky behaviors by currently smoking cigarettes, drinking alcohol, and using marijuana. Students with disabilities are more likely to report feelings of hopelessness and to consider and attempt suicide.
- Students with disabilities are more likely to be threatened, physically fight, be forced to have sex, and not go to school due to feeling unsafe. Students with disabilities are more likely to be overweight and get insufficient physical activity.



Children with Disabilities including Behavioral Health

Children with disabilities often receive a broad range of services that often include home and community-based services; behavioral health services; and/or hospital-based acute care services. Because their care needs are often very complex, many children with disabilities do not have community-based primary care providers, but rely on specialists for much of their primary care.

- Data from the 2003 National Survey of Children's Health indicate that: nearly one in seven (13.9%) Rhode Island children has asthma; 6.0% have/had frequent or severe headaches, including migraines; 4.7% have speech problems; 3.4% have bone, joint or muscle problems; 3.3% have a developmental delay or physical impairment; 2.8% have hearing or vision problems; 0.5% have autism; and 0.3% have diabetes. It should be noted that a child could have more than one of these conditions. The survey also found that 5.8% of parents would describe their child's health condition as severe.

- Additional survey data show that approximately one in ten (9.6%) Rhode Island children aged 3-17 had moderate or severe difficulties in the area of emotions, concentration, behavior or getting along with others. However, CSHCN were seven times more likely to have these difficulties (30.0%) than children without special health care needs (4.0%). Nearly one out of ten Rhode Island children (9.1%) received mental health care or counseling in the past year. The survey data also indicate that 7.4% of Rhode Island children have an emotional, developmental or behavioral problem for which treatment or counseling was needed. Specifically, 4.9% of respondents were told by a health professional that their child has behavioral or conduct problems and 7.0% have been diagnosed with depression or have anxiety problems.
- One out of ten children in Rhode Island (10.6%) has a learning disability and 8.7% have attention deficit disorder (ADD) or attention deficit hyperactive disorder (ADHD). Among the children with ADD or ADHD, 59.4% were taking medication for their condition. Approximately one-third, 30.1% of respondents reported that their child's mental and emotional health puts a burden on their family a great deal (7.9%) or a medium amount (22.2%).

(Source: Rhode Island Department of Health Program Data; 2005-2006 National Survey of Children with Special Health Care Needs)

Autism

More children in Rhode Island and nationally are being diagnosed with autism, which is a neurological disorder that affects a child's ability to communicate, process and respond to sensory information, and form social relationships. Those diagnosed with Autism Spectrum Disorders (ASDs) have a range of symptoms and abilities and experience challenges that range widely in severity.

- During the 2007-2008 academic year, the number of Rhode Island children aged 3-21 with autism continued to increase and rose to 1,472, representing a 15.9% increase from 2007, when there were 1,270 special education students with autism.

(Source: 2009 Rhode Island KIDS COUNT Factbook)

Adolescent Transition and Transfer to Adult Healthcare

Healthcare Transition, the process of change from child and family-centered healthcare to adult healthcare, is a critical part of the Medical Home concept. The goal of this transition for young adults with special healthcare needs is “to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood.”

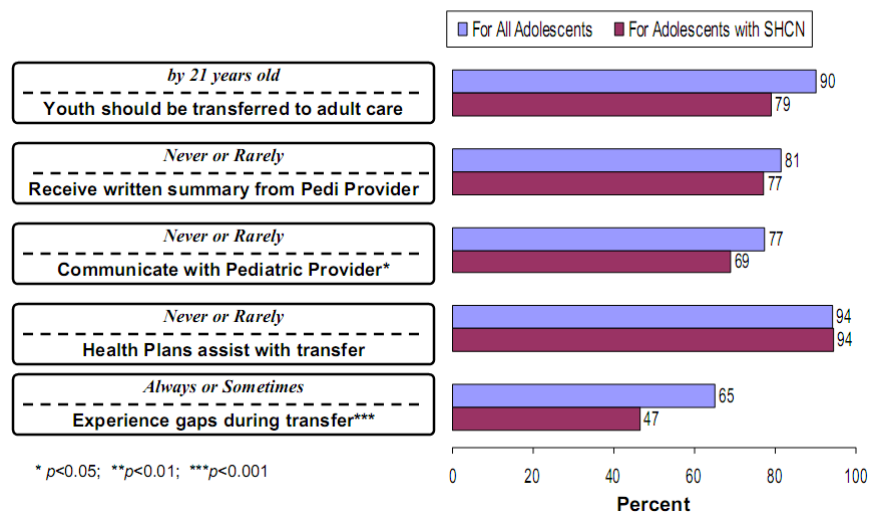
(Source: American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transition of young adults with special health care needs. *Pediatrics* 2002; 110:1304-1306.)

- According to 2005/2006 National Survey of Children with Special Health Care Needs youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence were 37.6% in Rhode Island compared to 41.2% nationally.

In 2006-2007, the Rhode Island Department of Health’s Office of Special Healthcare Needs (OSHCN) conducted a series of pediatric and adult primary care surveys to understand and identify current policies, practices, beliefs, and service delivery gaps related to the transition and transfer of youth with special healthcare needs from pediatric care to adult primary care. According to the surveys:

- The entry of young adults into an adult primary care practice is typically initiated by family members or friends.
- The majority of respondents reported higher levels of comfort in treating young adults with obesity, hypertension, and diabetes in comparison to treating young adults with sickle cell, spina bifida, cystic fibrosis, neuromuscular disease, and young adults who are technology dependent. The family practice physicians who provide continued care reported significantly higher comfort levels in treating young adults with mental health conditions (67%), cardiac conditions (70%), Down syndrome (74%), mental retardation (78%), autism (59%), and paraplegia (70%). The internal medicine physicians reported a significantly higher level of comfort in treating technology dependent young adults (30%).
- 79% of the respondents reported that young adults with special healthcare needs should be transferred to adult primary care by age 21. 77% reported they never or rarely receive a written transfer summary from the pediatric healthcare provider for their patients with special healthcare needs. 69% reported they never or rarely communicate with the pediatric care providers who previously cared for their patient with special healthcare needs. 94% reported that health plans never or rarely assist with the transfer, and 47% reported that young adults with special healthcare needs in their practice always or sometimes experience gaps in care during the transfer from pediatric to adult care.

Current Practices and Beliefs Related to Transition and Transfer
Among All Adult Primary Care Physicians (Internists and Family Physicians)



Additional Resources

For additional information about the materials presented in this, or any other data brief, please visit the Rhode Island Department of Health Website at:

www.health.ri.gov/

Or, to view the most recent publications from the Rhode Island Department of Health:

<http://www.health.ri.gov/publications/>

For additional information on any of the indicators presented in this, or any other data brief, as well as additional indicators, please visit Rhode Island KIDS COUNT at:

<http://www.rikidscount.org/matriarch/default.asp>