

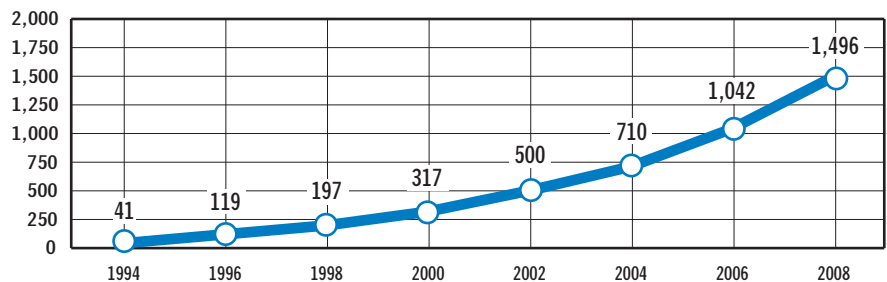
Issue Brief

RHODE ISLAND CHILDREN WITH AUTISM SPECTRUM DISORDERS

Autism Spectrum Disorders (ASDs) are a collection of brain development disorders that affect a person's ability to communicate, process and respond to sensory information, and form social relationships throughout their lives. Children diagnosed with ASDs have a range of symptoms and abilities and experience challenges that range widely in severity. Many children with ASDs face challenges in the following areas: social interaction, speech/language and communication, and repetitive behaviors and routines.¹

National research indicates that early, sustained and appropriate intervention can result in significant improvements in the quality of life, level of independent functioning in school and work and reduction of public costs associated with autism. However, many children with ASDs are not identified early. In addition, because of the high cost of interventions and the lack of skilled professionals to deliver them, many children do not receive timely and appropriate services.²

RHODE ISLAND STUDENTS RECEIVING SPECIAL EDUCATION SERVICES FOR ASDs, AGES 3-21, 1993-1994 TO 2007-2008 SCHOOL YEARS



Source: Rhode Island Department of Elementary and Secondary Education, Office of Diverse Learners, 1993-1994 to 2007-2008 School Years.

According to the Rhode Island Department of Elementary and Secondary Education, the number of children ages 3-21 with ASDs in Rhode Island increased from 41 in the 1993-1994 school year to 1,496 in the 2007-2008 school year. This is a 30 fold increase over the past 14 years. In 2008, students with ASDs made up 5% of the 29,612 Rhode Island children receiving special education services.³

The increasing numbers and rates of children with ASDs is largely attributable to improved awareness and diagnosis and a broadening of the educational definition of autism to include other ASDs, as well as other factors that may play a role.^{4,5}



NATIONAL PREVALENCE OF ASDs IN CHILDREN

- ◆ National estimates of ASD prevalence in children range from 1 out of every 150 children to 1 out of every 166 children. It is important to note that this rate includes both children with mild and more severe disorders.^{6,7}
- ◆ When a family has one child with an ASD, there is an estimated 4% – 8% chance that other siblings will also have an ASD.⁸
- ◆ The annual costs associated with caring for children with ASDs is estimated to be between 85% and 550% higher than for a typically-developing child. The average lifetime public expenditure per person with an ASD is approximately \$4.7 million.⁹



AUTISM AND ASDs: THE DEFINITIONS

- ◆ **Autism Spectrum Disorders (ASDs)** cover a wide range of behaviors, abilities, unique strengths, symptoms and severities. ASDs include autistic disorder, Asperger's Syndrome, and pervasive developmental disorder not otherwise specified (PDD-NOS or "atypical autism"). These three ASD conditions, along with Rett's Disorder and childhood disintegrative disorder, make up the broad diagnosis category of Pervasive Developmental Disorders (PDDs).
- ◆ **Autistic Disorder**, or "classic autism," is characterized by impaired social interactions and communication abilities. Symptoms may also include repetitive behaviors, sensory processing problems, circumscribed interests, resistance to change and diminished curiosity/ability to play. Symptoms usually emerge before age 3.
- ◆ **Asperger's Syndrome/Disorder**, like classic autism, is characterized by impaired social interactions, repetitive behaviors and resistance to change. However, there are no clinically significant speech delays in childhood (although there may be unusual speech patterns and other communicative difficulties) and no cognitive impairment.
- ◆ **Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)**, also known as "atypical autism," encompasses cases where there is marked impairment in social interactions, communication and/or repetitive behaviors or interests, but full features for other ASDs are not met.
- ◆ **Rett's Disorder** is a rare genetic disorder that is known to affect primarily girls and that can be identified using a specific genetic marker. It is characterized by typical development in the first few months followed by profound mental retardation and a loss of purposeful hand motor function.
- ◆ **Childhood Disintegrative Disorder**, considered a very rare disorder, is characterized by normal development through at least age 2, followed by the loss of previously acquired skills in expressive or receptive language, social skills or adaptive behavior, bowel or bladder control, or play or motor skills.

Source: *What are Autism Spectrum Disorders?* Retrieved July 24, 2008 from www.autism-society.org.

THE PREVALENCE OF ASDs IN RHODE ISLAND

BIRTH TO AGE THREE

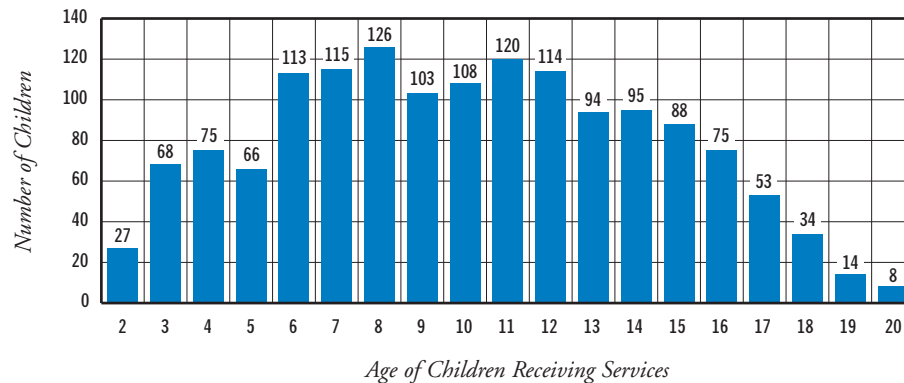
◆ Children under the age of 3 with developmental delays or who have a diagnosed physical or mental condition that is associated with a developmental delay are eligible to receive Early Intervention services according to Part C of the federal Individuals with Disabilities Education Act. The Rhode Island Department of Human Services administers the Early Intervention (EI) Program in Rhode Island. Children enrolled in EI are categorized under broad groupings which do not always translate to specific diagnoses. However, on June 1, 2008, 13 of the 1,792 children served by EI in Rhode Island were classified as having an autism diagnosis. This number is considered a significant underestimate in part because many children with ASDs are not formally diagnosed until after age 3.¹⁰

AGES THREE TO 21

◆ Public schools are required to provide all children with a free and appropriate public education. Students with ASDs may receive special education services and supports after being referred to their school's special education department for evaluation, eligibility determination and the creation of an Individualized Education Plan (IEP).¹¹

◆ Statewide data on children ages 3-21 with ASDs is available from the Office of Diverse Learners at the Rhode Island Department of Elementary and Secondary Education. In June 2008, there were 1,496 Rhode Island children receiving special education services under the category of autism (which since 2000 has included other ASDs as well).¹²

RHODE ISLAND CHILDREN RECEIVING SPECIAL EDUCATION SERVICES FOR ASDs, BY AGE, 2007-2008 SCHOOL YEAR



n = 1,496

Source: Rhode Island Department of Elementary and Secondary Education, Office of Diverse Learners, 2007-2008 School Year. Because children's ages are calculated as of December 1, 2007 and the census count is as of June 30, 2008, some children are listed as age two even though they did not begin to receive special education services until they turned three.

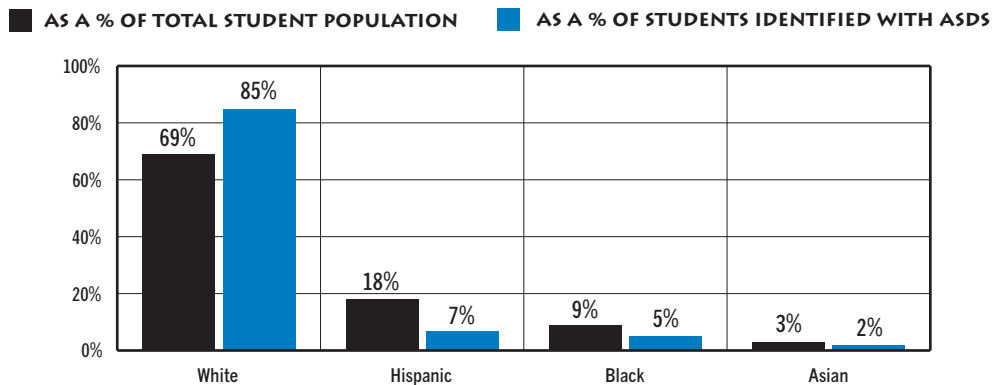
◆ The number of children identified as having ASDs for the purposes of special education peaks between ages 6 and 14.¹³ This raises concerns about early identification and the provision of appropriate services to younger children with ASDs.

◆ It is not known whether the smaller numbers of older students receiving special education services for ASDs is due to changes in student need, changes in eligibility for services, higher dropout rates among students receiving special education services, or other factors. Transition planning for middle and high school students with ASDs is critical to enable these students to graduate from high school and move on to meaningful further study, work and life. Special education laws in Rhode Island require that transition planning for students with disabilities begin no later than age 14.

DISPARITIES IN AUTISM SPECTRUM DISORDER DIAGNOSES

- ◆ There is little national data available regarding differences in ASD prevalence by race and ethnicity. A link between higher socio-economic status and increased likelihood of having a child with an ASD has been reported for a number of years. However, recent evidence has shown that the relationship is due in large part to higher diagnosis rates among higher-income families rather than to actual prevalence rates.¹⁴
- ◆ Boys are significantly more likely than girls to be diagnosed with an ASD, at a ratio of approximately 4:1.¹⁵

RHODE ISLAND CHILDREN WITH ASDs, BY RACE/ETHNICITY, 2007-2008 SCHOOL YEAR



Source: Rhode Island Department of Elementary and Secondary Education, Office of Diverse Learners, 2007-2008 School Year.

- ◆ In Rhode Island, White students are more likely than minority students to receive special education services under the category of autism. White students in Rhode Island make up 69% of the total student body but 85% of students receiving services for ASDs.¹⁶

POSSIBLE CAUSES OF ASDs

- ◆ While the specific causes of ASDs are unknown, both genetic and environmental factors are thought to play a role. Research regarding genetic causes has not yet identified exact pathways and markers due to their complexity and potential interactions with environmental factors. Some hypothesized environmental and other factors have included environmental toxins, immune system problems, antibiotics, immunizations, and mercury. It is also possible that a combination of factors may trigger ASDs.¹⁷ A multi-state federally-funded study was initiated by the U.S. Centers for Disease Control and Prevention (CDC) in 2006 to help identify and/or rule out risk factors for ASDs, including environmental toxins, immunizations and genetics.¹⁸
- ◆ The role of immunizations in causing autism has been the basis of a contentious national debate for a number of years. There have been a number of national studies regarding the connection between ASDs and thimerosal (a mercury-containing preservative that was used in the past in several childhood vaccines). None of these studies have confirmed a link between thimerosal and ASDs. The American Academy of Pediatrics (AAP), the American Medical Association (AMA), the Centers for Disease Control and Prevention (CDC), and the Institute of Medicine (IOM) agree that the current research does not support a link between thimerosal in vaccines and autism, and they recommend that parents follow approved vaccine schedules for their children to protect children from a number of infectious diseases that were once common and can result in death and disability.¹⁹



ASSESSMENT AND DIAGNOSIS

- ◆ When children with ASDs are diagnosed early in their lives, they can receive greater functional benefits from behavioral interventions. Their parents can have siblings screened who are at higher risk.^{20,21}
- ◆ The American Academy of Pediatrics (AAP) recommends both “surveillance,” which is the ongoing monitoring of children at all well-child pediatrician visits, and “screening,” the use of standardized developmental screening tools at prescribed intervals of 9 months, 18 months, 24 months, and 30 months. If the results of a screening test are positive or of concern, the child should be referred for more comprehensive evaluation by a provider trained in diagnosing ASDs.²²
- ◆ Rhode Island was the first state in the nation to incorporate the AAP recommendation of standardized developmental and ASD-specific screening requirement at 18 and 24 months in the Medicaid Early Periodic Screening Diagnosis Treatment (EPSDT) schedule. Rhode Island is also standardizing the guidelines for diagnosing children with ASDs through the efforts of the Rhode Island Department of Health Autism Advisory Board Work Group.
- ◆ In Rhode Island, data from the Department of Human Services and the Department of Education show that the number of children with ASDs increases with each year of age through early elementary school.^{23,24} This indicates that more can be done to improve parental education regarding early warning signs, and to improve screening approaches used by early intervention, child care and health care providers.



INTERVENTION AND TREATMENT OPTIONS

- ◆ There is no single treatment that works for all children with ASDs and interventions must be tailored to the specific needs of each child. Treatment and intervention options can be categorized into three main groups: behavioral approaches, biomedical approaches and medications.²⁵
- ◆ There is no known medical cure for ASDs, and most treatments focus on behavioral and educational interventions, including habilitative therapies. The complexity of ASDs requires coordination of a range of services such as physical therapy, occupational therapy, sensory integration therapy, special education, speech/language therapy, behavior management, therapies to build social interaction skills, and treatment of co-occurring physical and mental health disorders. In addition, while children with ASDs often exhibit symptoms common to developmental disabilities, mental health and/or physical disorders (including gastrointestinal problems), they also face unique challenges and may not be fully served by systems designed to serve the general population. For these reasons, specialized centers of medical research and treatment are important to individuals with ASDs.²⁶
- ◆ A variety of medications are available to alleviate some of the symptoms of autism or those of distinct but co-occurring conditions, including anxiety, attention deficit/hyperactivity disorder, depression, obsessive-compulsive disorder, other mental health disorders, seizures, gastrointestinal disorders, sleep disorders, and gross motor and fine motor difficulties. It is estimated that nearly half (45%) of children and adolescents with ASDs are treated with psychotropic medications.²⁷ Medications that treat these conditions are most often managed by a specialist such as a pediatric psychiatrist, neurologist, or developmental behavioral pediatrician.
- ◆ Parents of children with ASDs report difficulty accessing mental health services, locating providers experienced with treating children with ASDs, and dissatisfaction with the ASD treatment coverage provided by their health care plans.²⁸
- ◆ The use of complementary and alternative medicine (such as dietary restrictions or supplements, facilitated communication, and music therapy) also is common among children and youth with ASDs, although there is insufficient evidence to support or refute their use as treatment for ASDs.²⁹

NATIONAL RESEARCH: TEACHING CHILDREN WITH ASDS

Students with ASDs often need specific educational interventions and supports to succeed in school, achieve independence and to become productive community members. In 2001, the *National Research Council* published recommendations regarding education interventions for children with autism up to age eight. The National Research Council recommended the following:

- ◆ **Intervention should begin as early as possible.** There are windows of opportunity for improvement which are lost without early intervention.
- ◆ **Intensity matters.** Early intervention, preschool and other educational services should be provided for a minimum of 25 hours a week, 12 months a year. This level of engagement is needed to counter withdrawal and further a child's progress at key stages of early brain development.
- ◆ **The child should be engaged in systematically planned, developmentally appropriate educational activities towards identified objectives** with sufficient one-to-one and small group, daily attention to achieve such objectives.
- ◆ **Six kinds of interventions should have priority:** functional, spontaneous communication; social instruction in various settings; play skills with peers and toys; instruction leading to generalization of cognitive goals; proactive approaches to problem behaviors; and functional academic skills.
- ◆ **Instruction settings should maximize opportunities for interaction with typically developing children.**
- ◆ **Professionals who work with this population require specialized training and ongoing consultation** because of the complexities and unique features of ASDs.
- ◆ **Families need information and education** to participate in their children's education and assist in generalizing skills and behaviors.

Source: National Academy of Sciences, National Research Council. (2001). *Educating Children with Autism*. Washington, D.C.: National Academy Press.



MAXIMIZING REGULAR EDUCATIONAL OPPORTUNITIES FOR CHILDREN WITH ASDS

- ◆ Maximizing the opportunities of children with ASDs to interact with typically developing children is critical to improving outcomes for these children.³⁰ Of children with ASDs in Rhode Island who are under the age of 6, 67% were educated in separate classrooms or in separate schools or were in regular education settings less than 40% of the day; 30% were educated at least 80% of the time in regular education settings. Of children ages 6 and older, 44% were educated in separate schools or in residential facilities or were in regular education settings less than 40% of the day; 45% were educated at least 80% of the time in regular education settings.³¹
- ◆ Federal law requires that students with ASDs are provided appropriate services in the least restrictive environment possible. Students with ASDs who are educated in regular classrooms must receive appropriate supports to ensure success.

- ◆ In June 2007, the Rhode Island House Commission to Study the Education of Children with Autism was created in response to the rapidly growing numbers of children with ASDs in Rhode Island. The Commission continues to meet to develop a strategy to improve the educational outcomes of children with ASDs, focusing on diagnosis and assessment, prevalence, family impact and roles, educational goals and interventions, public policy changes, and personnel preparation.

**RH ODE ISLAND STUDENTS AGES 3-21 WITH AUTISM SPECTRUM DISORDERS (ASDs)
RECEIVING SPECIAL EDUCATION SERVICES, 2006-2007 SCHOOL YEAR**

DISTRICT OF RESIDENCE	TOTAL # OF STUDENTS	TOTAL # OF STUDENTS RECEIVING SPECIAL EDUCATION SERVICES	% OF ALL STUDENTS RECEIVING SPECIAL EDUCATION SERVICES	# OF STUDENTS WITH ASDs
Barrington	3,409	585	17%	39
Bristol Warren	3,459	504	15%	34
Burrillville	2,559	572	22%	29
Central Falls	3,481	933	27%	14
Chariho	3,572	488	14%	33
Coventry	5,441	1,051	19%	34
Cranston	10,406	2,143	21%	101
Cumberland	5,019	1,081	22%	60
East Greenwich	2,337	392	17%	37
East Providence	5,654	1,641	29%	53
Exeter-West Greenwich	2,008	393	20%	15
Foster	287	47	16%	NA
Foster-Glocester	1,566	167	11%	NA
Glocester	657	115	18%	NA
Jamestown	698	129	18%	15
Johnston	3,207	865	27%	45
Lincoln	3,258	586	18%	38
Little Compton	459	74	16%	NA
Middletown	2,418	546	23%	26
Narragansett	1,513	275	18%	16
Newport	2,249	574	26%	32
New Shoreham	140	26	19%	NA
North Kingstown	4,222	793	19%	27
North Providence	3,206	658	21%	25
North Smithfield	1,860	342	18%	16
Pawtucket	8,667	1,587	18%	74
Portsmouth	2,810	592	21%	40
Providence	25,015	5,338	21%	119
Scituate	1,767	278	16%	15
Smithfield	2,508	334	13%	19
South Kingstown	3,794	820	22%	51
Tiverton	2,036	478	23%	24
Warwick	10,841	2,587	24%	99
West Warwick	3,613	869	24%	22
Westerly	3,466	638	18%	45
Woonsocket	6,239	1,773	28%	68
<i>Charter Schools</i>	<i>1,748</i>	<i>231</i>	<i>13%</i>	<i>NA</i>
<i>State-Operated Schools</i>	<i>1,815</i>	<i>458</i>	<i>25%</i>	<i>NA</i>
<i>Core Cities</i>	<i>49,264</i>	<i>11,074</i>	<i>22%</i>	<i>329</i>
<i>Remainder of State</i>	<i>98,140</i>	<i>19,889</i>	<i>20%</i>	<i>936</i>
<i>Rhode Island</i>	<i>147,404</i>	<i>30,963</i>	<i>21%</i>	<i>1,265</i>

Core cities are Central Falls, Newport, Pawtucket, Providence, West Warwick and Woonsocket.

*Total number of students is the resident average daily membership for each district as calculated by the Rhode Island Department of Elementary and Secondary Education.

NA indicates that there are fewer than 10 students in this category; numbers are not shown in these instances to protect student confidentiality.

Source: Rhode Island Department of Elementary and Secondary Education, Office of Diverse Learners, 2006-2007 School Year.



IN-HOME THERAPY, PARENT EDUCATION AND FAMILY SUPPORT

◆ The families of children with ASDs are deeply affected by their situation, regardless of the severity of their children's disabilities. Parents of children with autism are more likely to suffer from depression and siblings of children with ASDs are more likely to be negatively affected than siblings of children with other special needs.³² Family support, parent training, in-home therapy and respite care are critical components of overall treatment of autism because they allow the family to participate in and generalize treatment and they provide much-needed relief from stress.³³

DEPARTMENT OF HUMAN SERVICES MEDICAID-FUNDED PROGRAMS FOR CHILDREN WITH SPECIAL NEEDS

- ◆ **Early Intervention (EI)** provides services for children under age three who have a developmental delay or disability.
- ◆ **Comprehensive Evaluation, Diagnosis, Referral and Re-evaluation (CEDARR) Family Centers** offer families of children with special needs information on specific disabilities, treatment options and referrals to community supports and assistance, including Medicaid-funded services, as well as limited clinical services for families waiting for Home Based Therapeutic Services.
- ◆ **Home Based Therapeutic Services (HBTS)** offer intensive in-home therapy to assist children, including children with autism, in achieving self-care, community participation, social growth and improved behavior. Providers are usually part-time trained paraprofessionals overseen by licensed health care professionals. Parents participate in developing their child's treatment plan and in helping their child develop new skills that are specified in the treatment plan.
- ◆ **Personal Assistance Services and Supports (PASS)** provides families with assistance and funding to hire and train a worker to implement personal therapy plans and help their child progress in the domains of daily living, safety, and socialization. By giving families the freedom to choose their own provider, PASS has tapped a non-traditional workforce, including relatives of the children being served. These providers may eventually train to become clinicians or therapists themselves.
- ◆ **Kids Connect** (formerly Therapeutic Services in Child and Youth Care) provides support for eligible children in child care settings, allowing them to socialize with typically developing peers.
- ◆ **The Respite Program** provides 100 hours of respite services per year per family and can serve up to 400 families in 2008.
- ◆ **Katie Beckett** is a special Medicaid eligibility provision that allows certain children with long-term disabilities or complex medical needs to obtain Rhode Island Medical Assistance coverage. Eligibility is based on the daily impact of the child's disorder and the extent of the child's disability as compared to a typically-developing child of that age. Only some children with ASDs qualify for coverage through the Katie Beckett provision due to the range of needs along the autism spectrum.

Source: The Rhode Island Department of Human Services, 2008. Notes: To receive these services, families must qualify for Medicaid. There are wait-lists for many of the above programs that also create a barrier for families trying to access services.

Watch Me Grow Rhode Island, a program of the Rhode Island Department of Health, works with primary care providers, child care providers and others to build a system of universal developmental screening for young children in order to increase early identification of developmental and behavioral concerns, including ASDs. The program also facilitates developmental interventions and communication between providers and families through training and technical assistance.

RHODE ISLAND RESOURCES

The Rhode Island Department of Elementary and Secondary Education

Ken Swanson, *Director of Diverse Learners*
(401) 222-4600 - www.ride.ri.gov

The Rhode Island Department of Human Services, Family Health Systems

Deborah Florio, *Administrator*
(401) 462-0140 - www.dhs.state.ri.us

The Rhode Island Department of Health, Division of Community, Family Health and Equity

Autism Advisory Board
Deborah Garneau,
Office of Special Healthcare Needs Chief
(401) 222-5929 - www.health.ri.gov

Special House Commission to Study the Education of Children with Autism

Representative Peter Palumbo
www.rilin.state.ri.us

Rhode Island Technical Assistance Project, Autism Support Center

Susan Constable, *Director*
(401) 222-8984 - www.ritap.org

The Autism Project of Rhode Island

Joanne Quinn, *Executive Director*
(401) 785-2666 - www.theautismproject.org

The Autism Society of Rhode Island

Lisa Rego
(401) 595-3241 - www.asa-ri.org

Families for Effective Autism Treatment of Rhode Island (FEAT/RI)

(401) 886-5015 - www.featri.org

The Rhode Island Parent Information Network (RIPIN)

(800) 464-3399 - www.ripin.org

Family Voices of Rhode Island

(401) 727-4144 - www.familyvoices.org

Parent Support Network (PSN)

(401) 467-6855 or (800) 483-8844 - www.psnri.org

Rhode Island Disability Law Center

(401) 831-3150 or (800) 733-5332 - www.ridlc.org

Rhode Island Legal Services

Veronika Kot, *Staff Attorney*
(401) 274-2652 or (800) 662-5034 - www.rils.org

Paul V. Sherlock Center on Disabilities at Rhode Island College (RIC)

(401) 456-8072 or (401) 456-8773 (TDD)
www.sherlockcenter.org

CEDARR Family Centers

About Families: (401) 365-6855
Family Solutions: (401) 461-4351
Families First: (401) 444-7703
Empowered Families: (401) 365-6103
www.dhs.state.ri.us/dhs/dcedarr.htm

The Groden Center

(401) 274-6310 - www.grodencenter.org

The Neurodevelopment Center

(401) 351-7779
www.neurodevelopmentcenter.com

Childhood Communications Services

Barry M. Prizant, *Director*
(401) 467-7008 - www.barryprizant.com

RHODE ISLAND MEDICAL CENTERS SERVING CHILDREN WITH ASDs

Center for Autism and Developmental Disabilities at Bradley Hospital

(401) 432-1189
www.lifespan.org/bradley/services/ddp

The Children's Neurodevelopment Center (CNDC) at Hasbro Children's Hospital

(401) 444-5685
www.lifespan.org/hch/services/neuro_cntr/

The Neurodevelopmental Center of Memorial Hospital of Rhode Island

(401) 729-6200 - www.mhri.org

The Behavior and Development Clinic at the Brown Center for the Study of Children at Risk at Women and Infants Hospital

(401) 453-7690
www.womenandinfants.org/body.cfm?id=889



RECOMMENDATIONS

ASSESSMENT AND DIAGNOSIS

- ◆ Increase access to training for pediatricians, Early Intervention providers, school personnel and other front-line staff, to promote earlier assessment and referral for diagnosis of ASDs. Special attention should be given to early identification of autism in low-income and minority communities where it is proportionately less likely to be diagnosed.
- ◆ Provide education to increase the skills of clinicians and service providers to discuss ASD diagnoses with families in a constructive manner, and to support culturally-competent approaches to assessment, referral and treatment.

EARLY INTERVENTION AND SPECIAL EDUCATION SERVICES

- ◆ Ensure that Early Intervention providers and school district staff have the expertise necessary to provide a continuum of services and supports to children with ASDs. Educational services should be consistent with best practices and research as summarized by the National Research Council, and provided within the home community, in the least restrictive environment appropriate to each child's needs.
- ◆ Ensure that all young children with ASDs are enrolled in Early Intervention, preschool or school consistent with the best practices and intensity of programming recommended by the National Research Council, including programming of at least 25 hours per week, 12 months per year, or for as other sufficient time and duration that appropriately meets the needs of each child.
- ◆ Develop a systematic, statewide strategy to fund the range of services required by children with ASDs. Explore interagency collaboration, statewide funds for children in need of intensive interventions, and an increased role for private medical insurance and Medicaid (including the issue of parity for mental health related services).

TRANSITION PLANNING FOR OLDER YOUTH WITH ASDs

- ◆ Families of youth with ASDs often face difficulties locating support services and providers willing to work with older children and youth. Expand the availability of high quality programs for youth with ASDs, including those located in middle and high schools. Improve incentives in order to increase the availability of programs and providers who work with older youth with ASDs.
- ◆ Many youth with ASDs will require services from the adult health care and mental health systems in order to participate effectively in the community as adults. Expand and support the availability of transition services for youth with ASDs to ensure that they have access to appropriate support services as they move into adulthood in order to improve outcomes and opportunities for this group of young people.
- ◆ Ensure that vocational and transition planning for all youth with ASDs who have an Individualized Education Plan (IEP) begins no later than age 14 as required by state special education regulations. Ensure that youth with ASDs in need of long-term services have an appropriate service plan in place by the time they exit school.

IN-HOME THERAPY, PARENT EDUCATION AND FAMILY SUPPORT

- ◆ Expand statewide capacity to provide in-home therapy, parent education, family support, respite and sibling support for families of children with ASDs through increased funding and public support.
- ◆ Expand education and outreach in the state about the resources available to youth with ASDs and their families.



RECOMMENDATIONS

ACCESS TO TREATMENT SERVICES

- ◆ Increase outpatient and community-based service capacity for children and youth across the spectrum of mild to severe ASDs, particularly those with dual ASD and mental health conditions, in order to reduce crisis care and institutional placement.
- ◆ Join the eight other states with legislation that requires private health insurance companies in the state to provide some level of diagnosis and treatment coverage for residents under age 21 with ASDs.

WORKFORCE DEVELOPMENT

- ◆ Increase collaboration between state agencies and Rhode Island institutions of higher education to ensure the availability of a trained workforce. Coursework that is focused on the unique needs of children throughout the autism spectrum should be included in the training programs and professional development opportunities offered to professionals working in education, speech/language and occupational therapy.
- ◆ Improve access to clinicians with knowledge of ASDs, including psychologists, pediatric psychiatrists, neurologists, and developmental pediatricians, by ensuring adequate reimbursement rates and resolving other workforce capacity issues, as well as by increasing training of medical students and professionals in the area of ASDs.
- ◆ Develop career paths for people who currently work part-time with children with ASDs and ensure adequate professional development and training to reduce turnover.

DATA COLLECTION AND RESEARCH

- ◆ Improve and centralize accurate and consistent data collection regarding ASDs in Rhode Island, in order to track autism prevalence rates and to plan for necessary services. All state agencies providing services to children with ASDs should coordinate data collection to ensure consistency, document the demographics of the identified population and measure prevalence by severity and diagnosis.
- ◆ Support research that identifies the causes of ASDs and that has a strong focus on finding effective interventions and treatments for children with ASDs.

NATIONAL RESOURCES

Centers for Disease Control and Prevention

www.cdc.gov/ncbddd/autism/

Autism Society of America

www.autism-society.org

American Academy of Pediatrics

www.aap.org

National Dissemination Center for Children with Disabilities (NICHCY)

www.nichcy.org

National Alliance for Autism Research (NAAR) / Autism Speaks

www.autismspeaks.org

Yale Child Study Center

www.info.med.yale.edu/chldstdy/autism/

OASIS (Online Asperger Syndrome Information and Support)

www.aspergersyndrome.org

Asperger's Association of New England

www.aane.org

Wrightslaw

www.wrightslaw.com

Future Horizons

www.futurehorizons-autism.com

First Signs

www.firstsigns.org



REFERENCES

- ^{1,7,8,11,25} *Rhode Island resource guide for families of children with autism spectrum disorders*. Rhode Island Department of Health, Office of Families Raising Children with Special Health Care Needs, April 2006.
- ^{2,4,6,9,14,15,17} Newschaffer, Craig J. et al. (2007). The Epidemiology of Autism Spectrum Disorders. *The Annual Review of Public Health*, 28, 235-258.
- ^{3,12,13,16,24} Rhode Island Department of Elementary and Secondary Education, Office of Diverse Learners, 1993-1994 and 2007-2008 school years.
- ^{5,19,21} *Facts for parents about vaccine safety*. (n.d.). Retrieved July 24, 2008, from www.aap.org/advocacy/releases/autismparent-facts.htm
- ^{10,23} Rhode Island Department of Human Services, 2008.
- ¹⁸ Center for Disease Control and Prevention. (2006). *CDC launches multi-state study on autism*. Retrieved July 22, 2008 from www.cdc.gov/od/oc/media/pressrel/r061006.htm
- ^{20,22} Johnson, Chris P, Myers, Scott M. & The Council on Children With Disabilities. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120, 1183-1215.
- ^{26,27,29,32} Myers, Scott M. Johnson, Chris P. & The Council on Children With Disabilities. (2007). Management of children with autism spectrum disorders. *Pediatrics*, 120, 1162-1182.
- ²⁸ *The Family Partners Project: The health care experiences of families of children with special health care needs*. (n.d.). Retrieved July 22, 2008 from www.familyvoices.org/pub/projects/behavioral.html
- ³¹ National Research Council. (2001). *Educating Children with Autism*. Washington, D.C.: National Academy Press.



ACKNOWLEDGEMENTS

Omayra Lopez, Joanne Quinn, The Autism Project of Rhode Island; Lisa Rego, Autism Society of Rhode Island; Rowland Barrett, M. Chris Borden, Bradley Hospital; Pamela High, Stephen Sheinkopf, Brown Center for the Study of Children at Risk; Lewis P. Lipsitt, Ph.D., Brown University; John Gaitanis, Chellamani Harini, David Mandelbaum, Child Neurodevelopment Center, Hasbro Children's Hospital; Elisabeth Kulcsar, Sharon Terreault, Meeting Street School; Robert Burke, Memorial Hospital of RI; Brenda Alejo, Cathie Ciano, Parent Support Network of Rhode Island; Kenneth Gu, Elizabeth Landry, Rhode Island Department of Elementary and Secondary Education; Deborah Garneau, William Hollinshead, Rhode Island Department of Health; Paul Choquette, Brenda Duhamel, Deborah Florio, Rhode Island Department of Human Services; Anne Mulready, Rhode Island Disability Law Center; Veronika Kot, Rhode Island Legal Services; Dawn Wardyga, Barbara Torres, Rhode Island Parent Information Network; Susan Constable, Rhode Island Technical Assistance Project.

Special thanks to the parents of children with ASDs who shared their experiences and recommendations during a special input session hosted by the Rhode Island Parent Information Network (RIPIN) and to those who participated in phone interviews.

Rhode Island KIDS COUNT is a children's policy organization that provides information on child well-being, stimulates dialogue on children's issues, and promotes accountability and action.

Primary funding for Rhode Island KIDS COUNT is provided by The Rhode Island Foundation, United Way of Rhode Island, The Annie E. Casey Foundation, Prince Charitable Trusts, CVS Caremark Charity Classic, Hasbro Children's Fund, Jessie B. Cox Charitable Trust, Neighborhood Health Plan of Rhode Island, UnitedHealthcare, Blue Cross & Blue Shield of Rhode Island, David and Lucile Packard Foundation, Pre-K Now, Nellie Mae Education Foundation and other corporate, foundation and individual sponsors.

Rhode Island KIDS COUNT Staff

Elizabeth Burke Bryant, Executive Director
Catherine Boisvert Walsh, Deputy Director
Leidy Alves, Administrative Assistant
Leanne Barrett, Policy Analyst
Jill Beckwith, Policy Analyst
Dorene Bloomer, Finance Director
Elaine Budish, Research Analyst
Raymonde Charles, Communications Coordinator
W. Galarza, Executive Assistant/Office Manager
Kathleen Keenan, Policy Analyst
Jessica Mack, Policy Analyst
Peter Davis, Brown University Medical School, Clerkship
Crystal Spence, Intern, Emory University

Rhode Island KIDS COUNT

One Union Station
Providence, RI 02903
401-351-9400
401-351-1758 (fax)
rikids@rikidscount.org
www.rikidscount.org



Production of the Issue Brief Series is made possible through the generous support of Hasbro Children's Fund