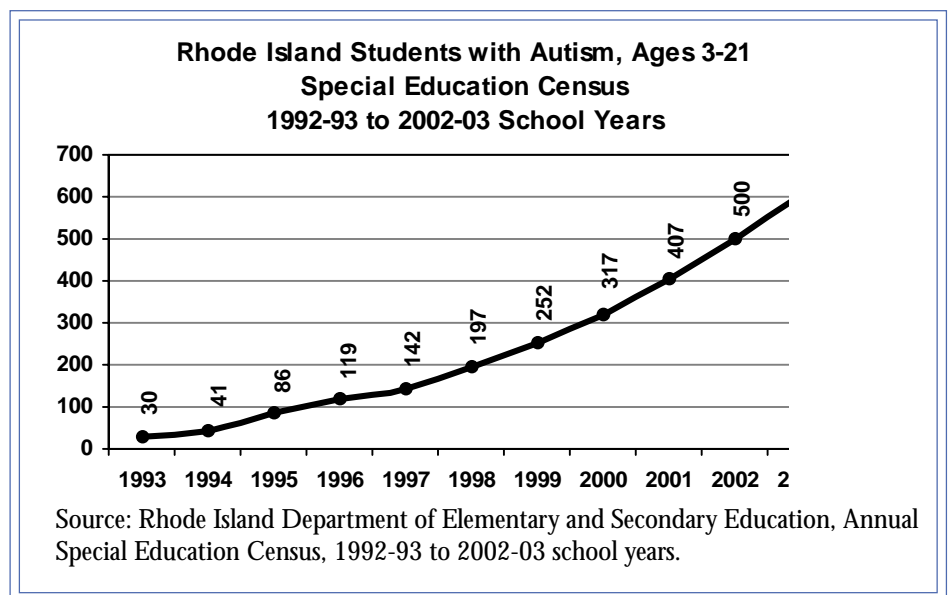


CHILDREN WITH AUTISM IN RHODE ISLAND

Autism is a neurological disorder that profoundly affects a person's ability to communicate, process and respond to sensory information, and form social relationships. Individuals diagnosed with Autism Spectrum Disorders (ASDs) have a range of symptoms and abilities, and experience challenges that range widely in severity.¹

Over the past decade, there has been growing concern and controversy over apparent increases in the childhood prevalence of Autism Spectrum Disorders, which until recently were considered rare (i.e. 4 per 10,000 children).² Recent studies suggest that the prevalence rate may be nearly 1 in 250 children (3.4 per 1000).³ Between the 1992-93 and the 2002-03 school years, the number of students ages 3-21 with autism reported in the Rhode Island Department of Education Special Education Census increased from 30 to 605.⁴

National research indicates that early, intensive, sustained and appropriate intervention can result in significant improvements in the quality of life, level of independent functioning and reduction of public costs associated with autism. However, due to a shortage of trained professionals, many children are not identified early. In addition, because of the high cost of intensive treatment and the lack of skilled professionals to deliver it, many children do not receive timely and appropriate services.^{5, 6}





PREVALENCE RATES, CAUSES AND DEFINITIONS

The national prevalence of autism spectrum disorders, which were once considered rare (i.e. 4 per 10,000 children), is uncertain. Autism is 3 to 4 times more common in males than in females.^{7,8}

- A 2003 study of the metropolitan area of Atlanta, Georgia showed an ASD prevalence rate of 3.4 in 1,000 children, a higher rate than childhood cancer, diabetes or Down Syndrome.^{9, 10}
- A 1998 study found a prevalence rate of 6.7 per 1,000 children with ASDs in Brick Township, New Jersey.¹¹
- U.S. Department of Education records indicate that autism rates in the special education census in every state increased between 1992-93 and 2001-02, in many instances by well over 1,000%.¹²
- A recent California report documented a doubling in the caseload of individuals with “autistic disorder” or “classic autism” served through that state’s developmental disabilities agency between 1998 and 2002. This was over and above a 273% increase between 1987 and 1998.^{13, 14}
- A review of epidemiological studies suggests that the rate for all Pervasive Developmental Disorders may be as high as 6 per 1,000 children.¹⁵

POSSIBLE CAUSES

The cause of the increase in prevalence of ASDs is unknown. Genetic factors play a major role in autism; however, they would not account for increases. Improved diagnosis, a broadening of definition, changes in special education laws and increased awareness may account for the change.¹⁶ Some studies hypothesize that environmental toxins¹⁷ or immunizations or thimerosal (a mercury preservative found in immunizations and being phased out nationally due to safety concerns), are behind the increase in prevalence.^{18, 19} Other studies have not confirmed a link to immunizations.^{20, 21} Still others believe that a combination of factors may be responsible.

Several federally-funded studies are investigating a variety of causes including environmental toxins, immunizations and genetics.²²

AUTISM: THE DEFINITIONS

Autism Spectrum Disorders (ASDs) cover a wide range of behaviors, abilities, unique strengths, symptoms and severities. Common areas that present challenges include social skills, speech/language and communication, repetitive behaviors and routines, anxiety and attention. ASDs include autistic disorder, Asperger’s Syndrome, and pervasive developmental disorder not otherwise specified (PDD-NOS or “atypical autism”). Along with Rett Syndrome and childhood disintegrative disorder, these three ASD conditions make up the broad diagnosis category of Pervasive Developmental Disorders (PDDs). Autism and ASD are used interchangeably in this issue brief.

Autistic Disorder, or “classic autism” affects social interaction, speech, sensory processing, and may be associated with mental retardation. Symptoms may also include repetitive behaviors, circumscribed interests, resistance to change and diminished curiosity/ability to play. Symptoms usually emerge before age 3.

Asperger’s Syndrome, like classic autism, affects a child’s social interactions, mannerisms, resistance to change and sensory processing. 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 (i.e. no mental retardation).

Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), also known as “atypical autism,” encompasses cases where there is marked impairment of social interaction, communication and/or stereotyped behavior or interests but full features for other PDD disorders are not met.

Rett’s Disorder is a rare disorder that is known to affect primarily girls. 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 regression and the onset of severe mental retardation.

Source: American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition. Washington, DC: American Psychiatric Association.



THE PREVALENCE OF AUTISM IN RHODE ISLAND

Rhode Island has no single data system that provides an unduplicated count of children with Autism Spectrum Disorders.

Birth to Age 3

The Department of Health, which administers the Early Intervention (EI) Program (for children up to age 3 with developmental delays), indicates that many children are not diagnosed with ASDs until after age 3. Children enrolled in EI are categorized under broad groupings, which do not readily translate to diagnoses. *Out of 3,950 children enrolled in Early Intervention between March of 2000 and September of 2002, 45 could be identified through EI records as having a primary, and 3 a secondary diagnosis of autism. During 2002, 11 children enrolled in EI had a diagnosis of autism.*²³

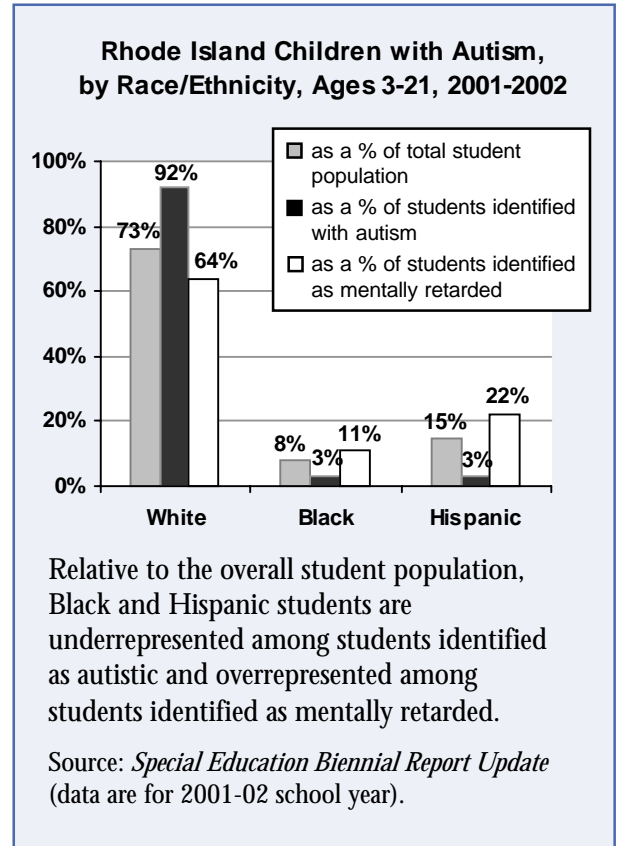
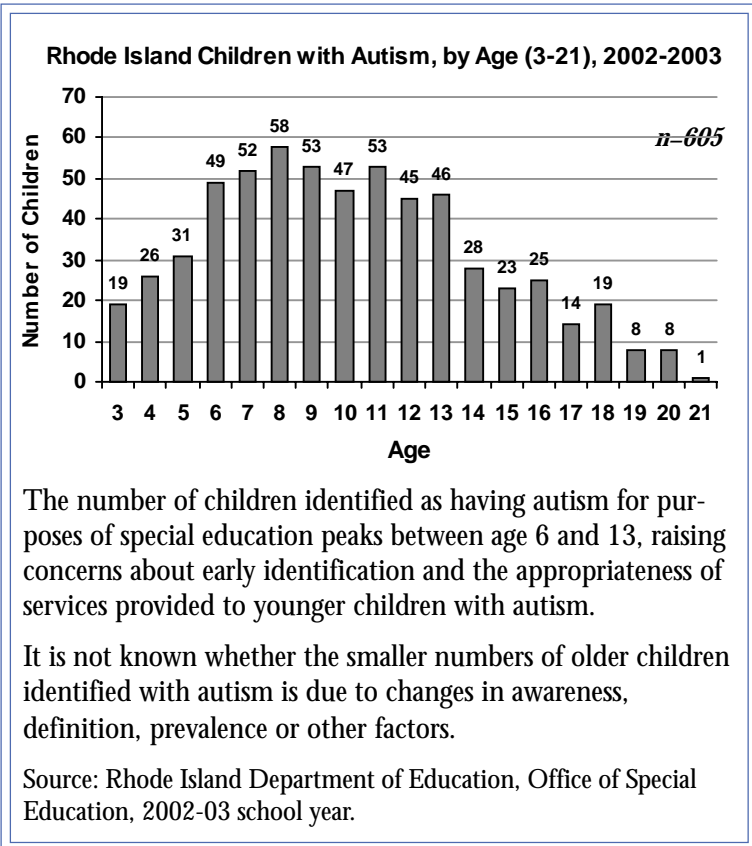
Ages 3 to 21

Virtually the only statewide source of data regarding rates of children with autism in Rhode Island is found in the special education census of the Rhode Island Department of Elementary and Secondary Education. The special education census annually reports the number of students receiving special

education services, by disability. These figures include children between the ages of 3 and 21. They are known to be an undercount because many children with autism are reported within other categories (mental retardation, speech/language or developmental delays).²⁴

According to the special education census, the number of children with autism in Rhode Island increased from 30 to 605 between the 1992-93 and 2002-03 school years. This is a 1,900% increase. The percentage of students with autism (as a percentage of all special education students) also increased. It is now fifteen times greater than it was ten years ago.²⁵

The reasons for increasing numbers and rates are unknown. They could reflect improved awareness and diagnosis, a broadened definition²⁶, increased prevalence, or a combination of factors. During the past ten years in Rhode Island, there has been no decline in other categories of disability in the special education census of a magnitude that might account for the full increase in autism rates.²⁷





ASSESSMENT, DIAGNOSIS, AND TREATMENT

NATIONAL RESEARCH: TEACHING CHILDREN WITH AUTISM

In 2001 the National Research Council published its recommendations with regard to interventions for children with autism up to age eight. Empirically validated programs share common characteristics:

- **Intervention should begin as early as possible.** There are windows of opportunity for improvement which are lost without early intervention.
- **Intensity matters. Early Intervention, pre-school and education 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:** the teaching of functional, spontaneous communication; social instruction in various settings; play skills with peers and toys; instruction leading to generalization of cognitive goals; positive 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 Research Council (2001). *Educating Children with Autism*. Washington, D.C.: National Academy Press.

ASSESSMENT AND DIAGNOSIS

According to the National Institute of Child Health and Human Development, the symptoms of autism are usually measurable by 18 months of age and formal diagnosis can be made by age two.²⁸ The NICHD recommends an autism screen during routine developmental surveillance at every well-child visit, followed by a protocol of investigation and screening in the event that any "red flags" are raised.²⁹

In Rhode Island, the Department of Health indicates that most children in the state with autism are not diagnosed before age three, indicating a need for training for child care and health providers in screening approaches.³⁰ Rhode Island Department of Education data suggests that some children may not be diagnosed until at least age six.³¹

EARLY INTERVENTION/PRESCHOOL

A synthesis of existing national research indicates that simply implementing what is already known about early, intensive and autism-specific interventions would likely result in approximately half of children with autism being able to function in a general education program by first grade, and that the long-term prognosis for adults would be substantially improved. Due to the cost of intensive services and the lack of trained staff, there is a significant gap between what is known and what is implemented.³²

In Rhode Island, the number of children enrolled in Early Intervention with an identifiable autism diagnosis is too small (11 children in 2002) to make any conclusion about a typical service package. While these children tend to receive more services than other children, service intensity and frequency vary widely.³³ Similarly, there is wide variation in the intensity and nature of services provided by school departments to children with autism between ages three and six. Preschool programs range from 12 to 30 hours per week and from 180 to 230 days per year.³⁴

PROMISING PRACTICES FOR EARLY INTERVENTION AND ASDs

New York State has taken the lead in developing research-based guidelines for the appropriate nature and intensity of services for young children with ASDs.³⁵ These guidelines are not prescriptive regulations, but are instead intended as best practices to be individualized to each child's needs. Massachusetts has certified Early Intervention Specialty Service Providers with training to work with children with ASDs.³⁶

Improving Outcomes, Promoting Inclusion, Reducing Costs

A 2002 study of children enrolled in special education, commissioned by the Rhode Island Legislature, indicates that per-pupil expenditures for children with autism are among the highest in the state, and that non-public school placements are the most expensive.³⁷ National research shows that early and intensive treatment for young children with ASDs improves outcomes and inclusion rates, thereby reducing restrictive and expensive placements.³⁸ In addition, due to the complexity of the disorder, the successful inclusion of children with autism depends on staff training and the availability of a continuum of supports and services which make it possible to meet a wide range of needs. In the absence of such expertise, children who need more than minimal support may be placed in unnecessarily restrictive and expensive settings due to a lack of alternatives.^{39, 40, 41}

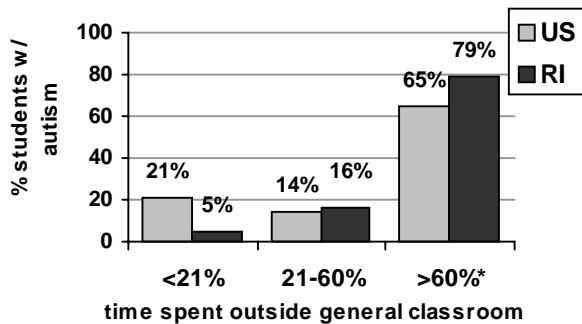
Technical Assistance

The Autism (ASD) Support Center of the Rhode Island Technical Assistance Project (RITAP), a collaboration between the Rhode Island Department of Education and Rhode Island College, provides consultation, technical assistance and training, and assists school districts with setting up model programs for children with autism. The Support Center recently expanded such classrooms to a total of six school districts. During 2002-2003 the Support Center presented 40 workshops to 1,049 school staff members and provided 92 consultations. The Support Center reports that while knowledge relating to teaching children with ASDs is improving, there is a continuing need for training, particularly for job-embedded training to ensure proper implementation of best practices in classrooms.⁴²

The Autism Project of Rhode Island, a nonprofit organization, sponsors trainings for parents and teachers, and has assisted 2 school districts with implementation of model demonstration classrooms. Demonstration classrooms must show a commitment to best practices. All staff must have significant training. The Project promotes replication of best practices throughout Rhode Island so students can be educated in home districts. School districts are encouraged to visit and learn from existing model classrooms. In 2003, 170 parents, teachers, clinicians, and home-based workers completed The Autism Project's nine-week training series and 30 professionals graduated from the five-day intensive summer ASD training.⁴³

Programs for Older Youth, Model classrooms in Rhode Island have been developed primarily for younger children. The Providence School District is in the second year of developing middle school and high school support programs for youth with ASDs. The Groden Center in Providence has experience working with youth with ASDs. The Sherlock Center on Disabilities at Rhode Island College provides technical assistance, including assistance with transition planning for youth with ASDs.⁴⁴ There is a continuing need in Rhode Island's local school districts for program development for older students with ASDs.

**Children with Autism, Ages 6-21:
Time Outside the General Classroom
RI and U.S., 1999-2000 School Year**



- Children with autism in Rhode Island are more likely to spend a greater portion of their day outside the general classroom than the national average.

Source: U.S. Department of Education (2002). *Twenty-fourth Annual Report to Congress on the Implementation of the IDEA*. Washington, D.C.

* includes separate facilities

EDUCATION AND TREATMENT APPROACHES

No single educational model or treatment approach for ASDs is most effective for every child. There is also an increasing tendency to draw from a variety of models within a program. Information about the following approaches is available online:

ABA (Applied Behavior Analysis)

www.featri.org

TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children)

www.teacch.com

SCERTS (Social Communication, Emotional Regulation, and Transactional Support)

depts.washington.edu/isei/review/iyc.html

Additional information about these and other treatments and treatment approaches is available on the following websites:

www.firstsigns.org

www.autisminfo.com

www.autism-society.org

ENHANCING SOCIAL ABILITIES

The nature and extent of challenges experienced by children on the autism spectrum varies greatly; however, one unifying challenge for all children with ASDs involves social interaction. Unaddressed social difficulties often lead to depression, exacerbating already significant neurological challenges.^{45, 46}

There is increasing recognition that therapies facilitating social interaction are as important as speech/language or occupational therapy.^{47, 48} A number of programs and some schools in Rhode Island offer “social groups” or “friendship groups” for children on the spectrum to teach and facilitate play, social interaction, appropriate social speech and/or friendship.

MEDICAL TREATMENT

While there is no known medical cure for autism, a variety of medications are available to alleviate some of the symptoms of autism or co-occurring conditions, including anxiety, obsessive compulsive disorder and other mental health disorders.⁴⁹ These medications must be managed by a pediatric psychiatrist, neurologist, or developmental behavioral pediatrician. The shortage of these clinicians in Rhode Island, as well as the reluctance of many providers to accept Medical Assistance or even private insurance (due to low reimbursement rates and complex paperwork), limits access and increases waiting times.⁵⁰

Other co-occurring conditions include but are not limited to seizures, gastrointestinal disorders, sleep disorders, gross motor and fine motor difficulties.^{51, 52, 53}

The complexity of ASDs requires coordination of a range of services such as physical therapy, occupational therapy, special education, speech/language therapy, behavior management, and treatment of co-occurring physical and mental health disorders. In addition, while individuals with ASDs often exhibit symptoms common to developmental disabilities, mental health and/or physical disorders, they also face unique challenges and may not be fully served by systems designed to serve other populations. For these reasons specialized centers of medical research and treatment are important to individuals with ASDs.

In Rhode Island, Bradley Hospital’s Developmental Disabilities Program provides services to children with developmental disorders, including autism, who also have a diagnosed serious emotional disturbance.⁵⁴ The Child Development Center at Hasbro Children’s Hospital provides assessment, counseling and followup for children with developmental disorders, including ASDs.⁵⁵ Memorial Hospital of Rhode Island has specialized programs for assessment services and a medical home for children with special needs, including those with ASDs.⁵⁶



IN-HOME THERAPY, PARENT EDUCATION AND FAMILY SUPPORT

The complexity of symptoms and needs which affect individuals with ASDs also impact on their families. National surveys indicate that families of children with autism are more stressed and more dissatisfied with services and systems than families of other children with special needs.⁵⁷ Parents of children with autism are more likely to suffer from depression and siblings are more likely to be negatively affected than family members of other children with special needs.^{58, 59}

Family support, parent training, in-home therapy and respite are critical components of overall treatment of autism because they allow the family to participate in and generalize treatment and provide much needed relief from stress.⁶⁰

Home Based Therapeutic Services (HBTS) in Rhode Island offer intensive in-home therapy to assist children, including children with autism, in achieving self-care, community participation, social growth and improved behavior. Due primarily to shortages of trained clinical and paraprofessional staff, as of October 2003 HBTS was serving 450 children and had a waiting list of 275 families, some of which have been waiting for over two years.⁶¹

Respite services are also very limited, serving approximately 400 families in Rhode Island and identified as a priority need by many families who are unable to obtain them.^{62, 63}

The Department of Human Services is initiating two new programs. Therapeutic Services in Child and Youth Care will offer support in licensed child care settings for children with special needs, including those with ASDs.⁶⁴ The Personal Assistance Services and Supports (PASS) program will offer consumer directed services, including an assistant, who could support children with special needs participating in community-based activities such as sports, summer camps and after-school activities. It is not yet known what the capacity of these programs will be.⁶⁵

FEDERAL INITIATIVES, RESEARCH AND RESOURCES

Congressional Autism Caucus

The Congressional Autism Caucus, formerly known as the Coalition for Autism Research and Education (CARE), was founded in 2001. It is a bipartisan forum in Congress where autism issues can be debated and where there is an opportunity to promote public awareness and research. Rhode Island Congressmen Patrick Kennedy and Jim Langevin are both members of the Caucus.⁶⁶

The Interagency Autism Coordinating Committee (IACC) and Annual Reports to Congress

The IACC was formed in 2001 in response to the federal Children's Health Act of 2000. Its purpose is to improve coordination among all federal agencies that deal with autism issues, to increase public understanding of relevant federal programs and services and to bring forward important matters for discussion. The National Institute of Health is the lead coordinating agency. Parents or legal guardians of individuals with Pervasive Developmental Disorders must be included as members of the Committee. The Children's Health Act also specifically requires the Department of Health and Human Services to provide an annual report to Congress regarding developmental disabilities and autism surveillance and research, education, service coordination and related matters.⁶⁷

Autism Summit Conference

On November 19-20, 2003, the U.S. Department of Health and Human Services and the Department of Education sponsored a conference mapping out a long-term interagency plan for autism diagnosis, early intervention, education and treatment, as well as biomedical research into causes and treatment.^{68,}

⁶⁹



RECOMMENDATIONS

Assessment and Diagnosis

- **Provide state-sponsored training for pediatricians, Early Intervention providers, school personnel and other front-line staff, to promote earlier assessment and referral for diagnosis of Autism Spectrum Disorders.** 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, and to support culturally-competent approaches to assessment and referral.**
- **Ensure that all young children with a diagnosis of autism spectrum disorder 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.** The shorter hours frequently associated with programming prior to first grade are of particular concern.
- **Expand the capacity of educational technical assistance projects such as the Rhode Island Technical Assistance Program, The Autism Project of RI and The Sherlock Center on Disabilities, to ensure that all school districts have the expertise necessary to provide a continuum of services and supports to children with autism across the spectrum.** 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.

Data Collection

- **Improve and centralize accurate and consistent data collection regarding autism in Rhode Island,** in order to track autism prevalence rates and to plan for necessary services. The RI Departments of Health, Education and Human Services should coordinate data collection to ensure consistency, to document the demographics of the identified population and to measure rates of prevalence by severity and diagnosis.
- **Consistent with the recommendation of the National Research Council, develop a systematic, state-wide strategy to fund the intensive services required by children with ASDs.** The NRC suggests exploring interagency collaboration, state-wide funds for children in need of intensive interventions, and Medicaid waivers.
- **Expand the availability of programs based on best practices for older children with ASDs, including those in middle and high school. Improve vocational and transition planning, beginning at age 14.**

Early Intervention and Education

- **Adopt benchmarks for the nature and intensity of Early Intervention services for children with ASDs, based on research.** Use these benchmarks to inform parents and providers about best practices that can be individualized to meet the needs of each child.



RECOMMENDATIONS

Workforce Development

- **Increase the involvement of institutions of higher learning in ensuring the availability of a trained workforce.** State agencies should collaborate with colleges and universities to ensure the availability of courses focused on the unique needs of children throughout the autism spectrum, for professionals in various disciplines including education, speech/language and occupational therapy. Such coursework should be a part of the curriculum for the various professional programs as well as a part of continuing education.
- **Improve access to clinicians with knowledge of autism, 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.

Outpatient Service Capacity

- **Increase outpatient and community-based service capacity for children and youth on the spectrum, particularly those with dual ASD and mental health conditions, in order to reduce crisis care and institutional placement.**

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 autism.**
- **State agencies and family advocates should work together to create a single clearinghouse of information and support with specialized knowledge for families of children with ASDs.** Families need access to such information immediately upon a child's diagnosis and throughout the child's life.

ON-LINE RESOURCES

Centers for Disease Control and Prevention

Definitions, publications, fact sheets.

www.cdc.gov

National Information Center on Children and Youth with Disabilities (NICHCY)

Funded by Office of Special Education Programs — Fact sheets, publications, links.

www.nichcy.org

National Alliance for Autism Research (NAAR)

Advocacy, research, fundraising.

www.naar.org

Yale Child Study Center

Research center on autism.

www.med.yale.edu

OASIS (Online Asperger Syndrome Information and Support)

www.aspergersyndrome.org

Asperger's Association of New England Support and information for individuals and families with Asperger Syndrome.

www.aane.org

Autism Coalition

Advocacy and fundraising for awareness and research.

www.autismcoalition.com

Autism Society of America

www.autism-society.org

Wrightslaw

Special education legal rights.

www.wrightslaw.com

Future Horizons

Publishing company of literature on autism.

www.futurehorizons-autism.com

First Signs

Promotes education of parents and professionals about ASD early warning signs and the need for early identification and treatment.

www.firstsigns.org

FAMILY SUPPORT AND SERVICE CO-ORDINATION

The Rhode Island Parent Information Network (RIPIN)

Training, information, support and advocacy for families.

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

Family Voices of Rhode Island

Part of national network for support of families of children with special needs.

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

Parent Support Network (PSN)

Family support and advocacy for families of children with behavioral and emotional challenges.

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

Rhode Island Disability Law Center

Free legal assistance for persons with disabilities in areas including education and other services.

(401) 831-3150 or (800) 733-5332

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

Training, technical assistance, outreach and research to promote full community membership for individuals with disabilities. Publishes *Transition Resources Guide* (available online).

(401) 456-8072 or (401) 456-8773 (TTY)

www.sherlockcenter.org

CEDARR Family Centers

Provide evaluation, case management and referral for children with special needs. Assist families with accessing services such as Home Based Therapeutic Services

About Families: (401) 331-2700

Family Solutions: (401) 461-4351

Families First: (401) 444-7703

Easter Seals: (401) 284-1000

CEDARR Family Center Resource Guide available on-line at: www.dhs.state.ri.us

STATE AGENCIES

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(401) 222-4600 ext. 2301

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REFERENCES

- ¹ American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Health Disorders*, 4th ed. Washington, DC: American Psychiatric Association.
- ^{2,3,7,9} Yeargin-Allsopp, M et al. "Prevalence of Autism in a US Metropolitan Area" in *Journal of American Medical Association*. 2003: 289:49-55.
- ^{4, 25, 27, 31} Rhode Island Department of Education, Special Education, 1992-2003.
- ^{5, 39, 60} National Research Council (2001). *Educating Children with Autism*. Washington, DC: National Academy Press.
- ^{6, 32, 38} Guralnick, M.J. editor. (2000). *The Effectiveness of Early Intervention*. Baltimore, MD: Paul Brooks Publishing Company.
- ^{8, 13} *Report to the Legislature on the Principal Findings from The Epidemiology of Autism in California: A Comprehensive Pilot Study* (2002). Davis, CA: University of California, Davis, M.I.N.D. Institute.
- ^{10,14} *Autistic Spectrum Disorders: Changes in the California Caseloads, An Update: 1999 through 2002*. (2003). Sacramento, CA: California Health and Human Services Agency.
- ¹¹ Centers for Disease Control and Prevention (2000). *Prevalence of Autism in Brick Township, New Jersey, 1998: Community Report*.
- ¹² United States Department of Education, Office of Special Needs, 1992-2003.
- ^{15, 16} Fombonne, E. (August 2003). "Epidemiological Surveys of Autism and Other Pervasive Developmental Disorders: An Update" in *Journal of Autism and Developmental Disorders*, Vol.33, No. 4.
- ¹⁷ Johnson, C. et al (December 1999). "Early Screening, Interventions, Key to Improving Autism Outcomes" in *American Academy of Pediatrics News*, (article reprint).
- ¹⁸ Geier, M. et al. "Thimerosal in Childhood Vaccines, Neurodevelopment Disorders, and Heart Disease in the United States" in *Journal of American Physicians and Surgeons*, Spring 2003: Vol 8, No. 1.
- ¹⁹ Bradstreet, J. et al. "A Case-Control Study of Mercury Burden in Children with Autistic Spectrum Disorders" in *Journal of American Physicians and Surgeons* (Summer 2003): Vol. 8, No. 3.
- ²⁰ Prober, C. (December 1999). "Evidence shows genetics, not MMR vaccine, determines autism" in *American Academy of Pediatrics News*, (article reprint).
- ²¹ Madsen, K. et al. (September 2003). "Thimerosal and the Occurrence of Autism" in *Pediatrics*, Vol. 112 No. 3.
- ²² *Report to Congress on Autism* (January 2003). Washington, DC: National Institute of Mental Health, National Institutes of Health, Department of Health and Human Services.
- ^{23, 30, 33} Rhode Island Department of Health, Early Intervention, 2000-2002.
- ²⁴ Lang, M. (1998). *Final Report: The State of Services and Treatment for Children with Autism Spectrum Disorders in Rhode Island*. Warwick, RI: Rhode Island Autism Project Committee.
- ²⁶ *Regulations Governing the Education of Children with Disabilities* (2000 and pre-2000 versions). Providence, RI: RI Department of Elementary and Secondary Education.
- ^{28, 29} National Institute of Child Health and Human Development, www.nichd.nih.gov/publications/pubs/autism/QA.
- ^{34, 40, 42} Interviews with Susan Constable and outline of Support Center accomplishments and identified needs, Rhode Island Technical Assistance Project, Autism Support Center.
- ³⁵ New York State Department of Health (1999). *The Guideline Technical Report: Autism/Pervasive Developmental Disorders*. Albany, New York
www.health.state.ny.us/nysdoh/eip/index.htm
- ³⁶ Massachusetts Department of Public Health (October 2003). *Specialty Service Providers for Children with Autism Spectrum Disorders*.
- ³⁷ *Children with Disabilities Study: Special Education in the Context of School Reform*, Commissioned by the Rhode Island General Assembly in July of 1999 (released September, 2002).
- ⁴¹ *Autism and Inclusion* (2003). Autisme Europe.
- ⁴³ Autism Project of Rhode Island (2003). *Draft Demonstration Project Classroom Standards and Project Description*.
- ⁴⁴ Interview with Nancy Stevenin and Karen Vessella, Providence School District (2003).
- ⁴⁵ Attwood, T. (1998). *Asperger Syndrome, A guide for Parents and Professionals*. London, GB: Jessica Kingsley Publishers.
- ^{46, 49, 53} Romanowski Bashe, P. et al. (2001). *The OASIS Guide to Asperger Syndrome*. New York, NY: Crown Publishers.
- ⁴⁷ Moyes, R. (2002). *Incorporating Social Goals in the Classroom*. London, GB: Jessica Kingsley Publishers.
- ⁴⁸ Gutstein, S. (2000). *Solving the Relationship Puzzle*. Arlington, TX: Future Horizons.
- ⁵⁰ Rhode Island KIDS COUNT (October 2002). *Children's Mental Health Services in Rhode Island*. Providence, RI.
- ^{51,67, 69} National Institute of Mental Health (NIMH).
www.nimh.nih.gov
- ⁵² Horvath, K. et al. (November 1999). "Gastrointestinal abnormalities in children with autistic disorder" in *The Journal of Pediatrics*, Vol 135, No. 5.
- ⁵⁴ Bradley Hospital Developmental Disabilities Program.
www.lifespan.org/services/childhealth/bradley/ddp
- ⁵⁵ Child Development Center at Hasbro Children's Hospital.
www.lifespan.org/services/ChildHealth/CDC/
- ⁵⁶ Neurodevelopmental Center and Primary Care Center for Children with Special Needs at Memorial Hospital of Rhode Island. www.mhri.org
- ⁵⁷ Wells, N. et al. (2000). *What Do Families Say About Health Care for Children with Special Health Care Needs?* Boston, MA: Family Voices.
- ⁵⁸ Fisman, S. et al. (November 1996). "Risk and Protective Factors Affecting the Adjustment of Siblings of Children with Chronic Disabilities" in *Journal of the American Academy of Child and Adolescent Psychiatry*, Vol. 35, No. 11.
- ⁵⁹ Harris, S. editor (2003). *Siblings of Children with Autism, A guide for Families*. Bethesda, MD: Woodbine House, Inc.
- ^{61, 62} Rhode Island Department of Human Services, 2003.
- ⁶³ Griffin, J. (1998). *Health Care Needs of Children with Disability on Medicaid: Results of Caregiver Survey*. MCH Evaluation Inc.
- ⁶⁴ State Department of Human Services (April 15, 2003). *Certification standards, Therapeutic Child and Youth Care*.
- ⁶⁵ State Department of Human Services (September 23, 2003). Rough Draft Personal Assistance Services and Supports (PASS)
- ⁶⁶ Autism Coalition, www.autismcoalition.com/caucus.asp
- ⁶⁸ Rhode Island Technical Assistance Project, Autism Support Center summary of Autism Summit Conference (2003).

RHODE ISLAND AUTISM RESOURCES

Rhode Island Technical Assistance Project, Autism Support Center
Technical assistance, professional development and policy analysis to promote improved educational services to children with ASDs.
Susan Constable
(401) 222-4600, ext 2014

The Autism Project of Rhode Island
Training and technical assistance for school districts, professionals and parents.
(401) 785-2666 / www.theautismproject.org

The Autism Society of Rhode Island
Jennifer Hanley, Deputy President
(401) 738-8922 / acastle2@netzero.net

Families for Early Autism Treatment of Rhode Island (FEAT/RI)
Education, advocacy and support for families of children with autism.
(401) 886-5015 / www.featri.org

Bradley Hospital, Developmental Disabilities Program
Specializes in providing services to children with co-occurring serious emotional disturbances and developmental disabilities such as autism.
(401) 432-1189 / www.lifespan.org/services/childhealth/bradley/ddp

The Child Development Center, Hasbro Children's Hospital
Assessment, diagnosis and counseling.
(401) 444-5685 / www.lifespan.org/services/childhealth/cdc

Memorial Hospital of Rhode Island
Primary Care Center for Children with Special Needs
Serves as a medical home for children with special needs including autism.
(401) 729-2582 / www.mhri.org
Neurodevelopmental Center
Assesses, treats and provides follow-up for children, including those with ASDs.
(401) 729-6200 / www.mhri.org

The Groden Center
Day and residential treatment, education, community consultation, in-home programs for children and youth including those with ASDs.
(401) 274-6310 / www.grodencenter.org

The Neurodevelopment Center
Assessment, treatment and school consultation services for individuals with neurological disorders including ASDs.
(401) 351-7779 / www.neurodevelopmentcenter.com

Childhood Communication Services
Barry M. Prizant, Director
Early identification and assessment of young children, school consultation.
(401) 467-7008 / www.barryprizant.com

Note: Due to space considerations, this is not an exhaustive list of providers or resources. Additional listings are available through the websites cited above and through the CEDARR Family Center Resource Guide, www.dhs.state.ri.us or Family Voices Resource Guide, www.familyvoices.org.

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