

IMPROVING OUTCOMES FOR CHILDREN WITH SPECIAL NEEDS

Children with special needs are those who have a chronic condition that requires educational, health and related services of a type or amount beyond that required by children generally.¹ Special needs can be physical, developmental, behavioral and/or emotional. Some conditions that give rise to special needs include mental retardation, attention deficit disorder, asthma, autism, sensory impairments, communication disorders, and congenital diseases.^{2, 3, 4}

The challenges faced by children with special needs and their families vary widely, depending on the nature of the disability, the child's age, family education, economic status, language and residence.

- The extent to which children with special needs are able to reach their potential and enjoy full participation in their community is related to a number of factors including access to services that meet their health, education and socio-emotional needs and the extent to which families receive supports to care for their children.
- Improved outcomes for children with special needs are achievable with high expectations, early and intensive services, and interventions that are based on the best available research.
- Positive outcomes for children with special needs reduce societal costs by maximizing lifetime earnings, family stability and good health; and reducing dependency, delinquency and costly institutional care.

According to Census 2000, there are 21,713 (9.3%) children with disabilities in Rhode Island between the ages of 5 and 20.* Disability is defined in the Census as having a long-lasting physical, mental, or emotional condition that can make it difficult for a person to walk, climb stairs, bathe, learn, remember or go outside alone to work. Rhode Island's rate of children with disabilities is exceeded only by Arkansas and Washington, D.C.⁵ The reasons for Rhode Island's higher rate are unknown. They may reflect a real difference in prevalence or better access to health insurance, diagnosis and treatment or a combination of factors.

*Prevalence rates for younger children were not included in this particular Census analysis, but are, of course, equally important.



DEFINING SPECIAL NEEDS

There is no single definition of special needs or disabilities. The terms often have particular meanings or legally-defined eligibility criteria depending on the program or system of care which is at issue.

- The Maternal and Child Health Bureau of the U.S. Department of Health and Human Services states that “children and youth with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”⁶
- A different set of complex federal criteria, with a focus on developmental delay, is used to define children who qualify for Early Intervention services. Yet another set of definitions focused on specific disability categories and their impact on learning applies to children who qualify for special education services. To complicate things further, states have some latitude in defining the scope of specific disability categories for purposes of both Early Intervention and special education programs.⁷
- Various surveys and studies, including those used by the U.S. Bureau of the Census, at times use slightly different definitions of disability.
- Finally, families and advocacy organizations have varying perspectives on how disabilities, challenges, special needs and learning differences should be defined or perceived.

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For purposes of this Issue Brief, the term “special needs” is used broadly to encompass the wide range of needs of all children (and their families) who have health, developmental, learning, access and other needs, challenges or differences not shared by most children generally. Where a specific system of care or study with a particular set of definitions or eligibility criteria is discussed, the definition or reference to the definition is noted.

DISABILITY-SPECIFIC RESOURCES IN RHODE ISLAND

Autism Society of Rhode Island
Jennifer Hanley, Deputy President
(401) 738-8922

Autism Project of RI
Joanne Quinn, Executive Director
(401) 785-2666
www.theautismproject.org

Brain Injury Association of America
Sharon Brinkworth, Executive Director
(401) 461-6599
www.biausa.org

Children and Adults with Attention Deficit Disorder
Jeanne Connery
(401) 943-9399
www.chadd.org

Down Syndrome Society of RI
Claudia Lowe, Coordinator
(401) 463-5751
www.dssri.org

Dual Sensory Impairment Project of the University Affiliated Program
Susan Dell, Project Coordinator
(401) 456-8557
www.sherlockcenter.org

Epilepsy Foundation of Massachusetts and Rhode Island
William Murphy, Executive Director
(617) 506-6041 or (888) 576-9996
www.epilepsyfoundation.org/massri/

Families for Early Autism Treatment of RI
(401) 886-5015
www.featri.org

Muscular Dystrophy Association
(401) 732-1910 or (800) 572-1717
www.mdausa.org

National Alliance of the Mentally Ill of Rhode Island
Nicki Sahlin, Executive Director
(401) 331-3060
ri.nami.org

National Multiple Sclerosis Society, RI Chapter
Kathy Mechnig, Chapter President
(401) 738-8383
www.nmssri.org
www.nationalmssociety.org/ri/home

RI Association of the Deaf (RIAD)
Maria Okwara, President
TDD: (401) 431-0465
Relay: (800) 745-6575
members.aol.com/earnesto/riad.html

RI Association of Retarded Citizens (ARC)
(401) 463-9191

RI Developmental Disabilities Council
Marie Citrone, Executive Director
(401) 737-1238
www.riddc.org

RI Parents of Blind and Visually Impaired Children
Elizabeth Frampton, President
(401) 658-0516
www.ripbvic.com

RI Speech-Language-Hearing Association
Sheryl C. Amaral, President
(401) 455-7472
www.risha.info/

Services for the Blind and Visually Impaired
Linda Hughes
(401) 222-2300 ext. 423
www.ors.state.ri.us/sbvi.htm

United Cerebral Palsy of RI
Lowell Roberts, Executive Director
(401) 728-1800
www.ucpri.org

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



THE IMPACT OF UNADDRESSED SPECIAL NEEDS

When the special needs of children are not addressed, the negative impact on the child and the family is often lifelong and societal costs are high.

FAMILY CRISIS

- ***Crisis Care and Institutionalization.*** The lack of preventative services leads to crisis-driven care and expensive hospital or institutional placements.⁸
- ***Stressed Families.*** The majority of caregivers of children with disabilities in Rhode Island feel overwhelmed by their child's needs.⁹

EDUCATIONAL OUTCOMES

- ***Disproportionate Suspensions.*** During the 2001-2002 school year, 28% of suspensions involved children with special needs (as evidenced by an Individualized Education Plan), while children with IEPs constituted 22% of students. In five school districts over 40% of suspensions involved students with IEPs.¹⁰
- ***Dropouts.*** In Rhode Island the high school dropout rate in 2001-2002 for students with disabilities (31%) is higher than for all students (12%).¹¹

DEPRESSION, MALTREATMENT AND DELINQUENCY

- ***Depression.*** Nationally, 31% of children with disabilities report feeling sad or depressed as compared with 17% of other children.¹²

- ***Abuse and Neglect.*** Children with disabilities are up to four times as likely to be maltreated as children without disabilities.¹³
- ***Crime and Delinquency.*** As of December 1, 2002, 41% of youth at the Rhode Island Training School were receiving special education services, 55% were receiving substance abuse treatment and 12% were receiving psychiatric treatment.¹⁴

EMPLOYMENT AND ECONOMIC IMPACT

- ***Lower Youth Employment Rates and Earnings.*** Youth with disabilities are less likely than all Rhode Islanders to work full-time and more likely to have lower wages.¹⁵
- ***Poverty.*** Poverty and disability are correlated among both children and adults. Risks associated with poverty can increase the likelihood of some disabilities and disabilities can impact a family's economic security.^{16, 17}
- ***Lower Adult Employment Rates.*** The disability of a child is associated with a reduction in the odds that the mother can work, increasing the likelihood the family will need to rely on welfare benefits for support. Unaddressed special needs can also interfere with the subsequent ability to work as an adult.¹⁸



THE PROMISE OF POSITIVE OUTCOMES

Outcomes for children and youth with special needs can be improved and the societal costs of disability reduced by fully implementing knowledge about best practices. For example:

- Early and high quality programs for young at-risk children or children with identified disabilities yield sustained improvements in outcomes.¹⁹
- Implementing research-based practices to assist children with special needs or at risk of school failure within the public education system will improve educational outcomes. Such practices include early identification, parental involvement, preschool intervention with sustained early grade assistance, improved teacher training and higher expectations.^{20, 21}
- Multiple agencies can be successfully coordinated to achieve comprehensive, effective and affordable health care by providing a continuum of services and minimizing high-end crisis care.²²
- Enforcement of nondiscrimination laws and expansion of opportunities for community participation reduce barriers of isolation, stigma and low expectations, allowing children with special needs to achieve their full potential while reducing personal and societal costs of dependency.^{23, 24}



INCLUSIVE AND EFFECTIVE SYSTEMS

*"[I]t often takes personal experience or the experiences of a loved one to become aware of what it means to deal with disability. Disability issues, like other minority experiences, challenge us to see the world through the eyes of others ... perhaps, one day, ourselves."*²⁵

An effective system of care for children with special needs, has adequate capacity and coordinates early childhood, education, health and community needs.^{26, 27, 28, 29} An effective system of care is:

- Family and child-centered, strength-based, and culturally competent.
- Seamless and coordinated.
- Accessible for early assessment, diagnosis and treatment.
- Adequate in capacity, including a trained workforce and a continuum of services.
- Dedicated to providing services in natural, least restrictive settings, and promoting inclusive and accessible environments.
- Based on the best available research and promising practices with regard to the nature and intensity of services and subject to ongoing quality control and evaluation.
- Active in addressing attitudinal barriers such as low expectations and stigma.



PREVENTING DISABILITY

Preventing disabilities before they arise is of increasing importance as advances in medical science have increased survival rates of children with severe disabilities or at risk for disabilities due to very low birth weight or prematurity.³⁰

Access to preconception and prenatal health and counseling are among the key aspects of prevention. While Rhode Island is best in the nation in providing timely prenatal care, women in core cities (Rhode Island communities in which more than 15% of children live below the poverty level) are twice as likely as other women to receive delayed prenatal care and are more likely to have higher rates of low birthweight.^{31, 32} Other areas for prevention include avoiding prenatal and infant exposure to toxic hazards and injury prevention.³³

DIVERSITY AND DISABILITY

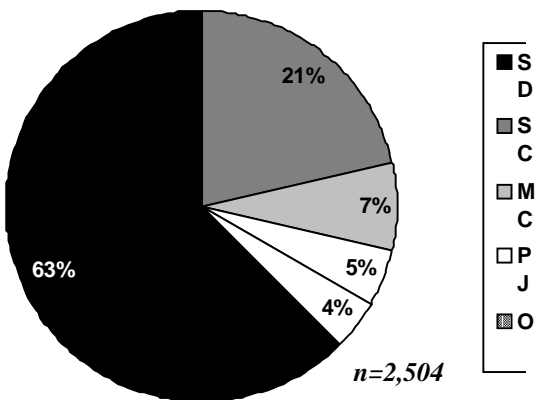
The incidence of disability is higher among low-income and minority families yet these families are less likely to provide input into policy and program design than other families.³⁴ *Building on Strengths of Diversity* is a federally-funded project under the leadership of the Parent Support Network, with a focus on building cultural and linguistic competence and family-centered practice into health, education and mental health systems that serve children with special needs in Rhode Island. The project's Family Leadership Team includes culturally diverse parents, service providers, advocates and representatives from various state agencies. The project seeks to identify approaches that will ensure that state systems are truly responsive, respectful and reflective of linguistic, ethnic and cultural diversity.³⁵

EARLY IDENTIFICATION AND INTERVENTION

EARLY INTERVENTION: CHILDREN WITH DISABILITIES, BIRTH TO AGE 3

The federal Individuals with Disabilities Education Act, Part C (IDEA) requires states to identify and to provide Early Intervention services to children from birth to age 3 who are developmentally delayed or have been diagnosed with a physical or mental condition that has a high probability of resulting in developmental delay. States may also choose to serve children more broadly at risk of delay. How broadly states define eligibility for Early Intervention affects the percentage of children served. Rhode Island's definition does not include children who are at risk for developmental delay.³⁶ Rhode Island's Early Intervention Program is administered by the Department of Health. As of December 1, 2000, Rhode Island served 2.51% of its child population ages birth to 3 in Early Intervention, above the U.S. average of 1.99% but below the rates of three neighboring states, New Hampshire (2.77%), Connecticut (2.90%), and Massachusetts (5.15%).³⁷

**Children Enrolled in Early Inte
Rhode Island, January - Decem**



- Of the 2,504 children served in Early Intervention in 2002, 65% were male. Sixty-two percent of the children served were White, 18% were Hispanic, 6% were Black, 5% were of mixed race, 2% were Asian and 7% were other or unknown.³⁸
- Rhode Island currently has a data system that tracks services provided in Early Intervention by the nature of the service. The capacity exists to track services provided by specific disability.³⁹

* without specific diagnosis (1,566)

** specific diagnosed condition affecting development (535)

*** at least 4 identified biological and social risks (shown by research to lead to developmental delays) (177)

**** provisionally eligible based on professional judgment (119)

***** 78 children with completed goals awaiting discharge; 29 for whom eligibility is missing

Source: Rhode Island Department of Health, Early Intervention, 2002.

BENCHMARKS AND BEST PRACTICES IN EARLY INTERVENTION

On a national level and in Rhode Island, there is increasing interest in benchmarks regarding outcomes, intensity, duration and range of Early Intervention services received by children with specific impairments. There is a growing consensus that such standards would aid the delivery of consistent, high quality and effective services.⁴⁰

Sufficient research does exist to develop such standards for an increasing number of disorders.⁴¹ New York State has taken the lead in this area by synthesizing existing research into guidelines for assessment and early intervention for autism and for communication disorders, and soon-to-be finalized guidelines for motor disabilities, Down Syndrome, hearing loss and visual impairment. These guidelines are not prescriptive regulations; they are intended as best practices to inform individualized decisions by providers and families.⁴²

Rhode Island is currently in the process of developing standards for Early Intervention hearing and vision services.⁴³

Source: NY State Department of Health, Early Intervention Program. www.health.state.ny.us/nysdoh/eip/index.htm



PRE-SCHOOL: CHILDREN WITH DISABILITIES (AGE 3-5)

The IDEA Part B requires that children with certain identified special needs between the ages of 3 and 5 receive special education services. In Rhode Island these services are provided by local school districts. During the 2002-2003 school year, 2,516 children ages 3-5 received special education services in Rhode Island.⁴⁴ These services are provided in a variety of settings including child care and schools.

While approximately 70% of children exiting Early Intervention are referred to special education, there is no data indicating how many of them in fact continue to be served in a special education pre-school setting. The transition at age 3 from Early Intervention to special education is fre-

quently identified as a point of difficulty, with service reductions or interruptions for up to two years because the eligibility criteria, services, and the agencies administering the two programs are different. In Rhode Island the Department of Health and the Department of Education are collaborating to fund a transition coordinator to improve this process. In its federally-mandated five year Improvement Plan under the IDEA, Rhode Island has identified several steps to improve the process, including improved data collection, technical assistance through a Transition Leadership Team, an Early Childhood Transition Network (including parent consultants) for oversight, and development of transition standards.⁴⁵



SERVING AT-RISK CHILDREN, BIRTH TO AGE 5

Research has demonstrated the long-term cost effectiveness of high quality programs for young children at risk of poor outcomes due to environmental and socio-economic risks.⁴⁶ The Chicago Longitudinal Study, an ongoing 17-year study of an extended early intervention program for children ages 3-9 and their parents, recently found *a 41% reduction in special education placement rates for preschool participants* and a seven-fold return on investment due to earnings, reduced costs of criminal involvement and savings on school remedial services. Earlier and longer program participation resulted in the highest returns. This program, implemented in urban public school settings, holds promise for large scale replication.⁴⁷

In Rhode Island, many children at risk of developmental delay or other poor outcomes are not eligible for Early Intervention or special education but may be referred to other programs. None of these programs has

the capacity to serve all children in need of services.

- **Early Head Start** provides supports to vulnerable families during pregnancy, provides child development services for infants and toddlers, and supports healthy family functioning. As of October 2002 there were 409 children enrolled in Early Head Start in Rhode Island.⁴⁸
- **Head Start and Comprehensive Child Care Networks** provide comprehensive early childhood services for low-income preschool children, including education, health, nutrition, and mental health services. In Rhode Island, 53% of eligible 3 and 4 year-olds (2,634 children) were served in Head Start in 2002. Another 260 children were enrolled in Comprehensive Child Care Networks, a state program modeled on the Head Start standards.^{49, 50}

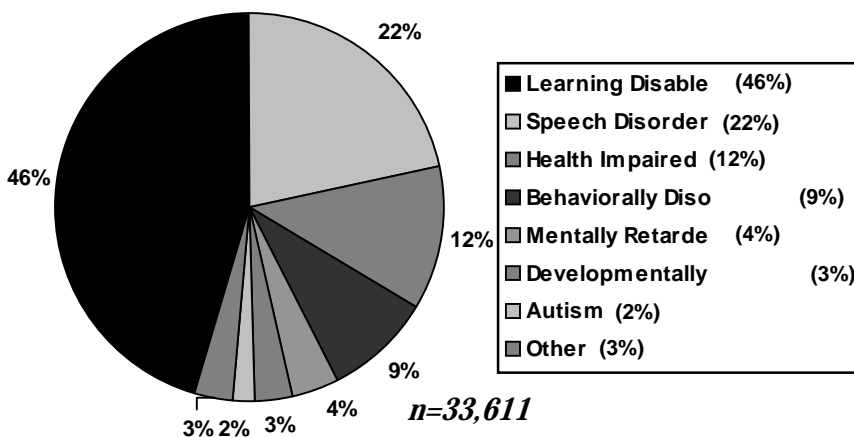
SPECIAL EDUCATION

*"[O]ur educational system must provide opportunities for kids to utilize...their strengths and their affinities.... A school for all kinds of minds must embrace the conviction that every learner has distinct educational needs.... No mind should have to beg to differ."*⁵¹

The Individuals with Disabilities Education Act, Part B (IDEA) requires school districts to identify and evaluate students whom they have reason to believe have disabilities which affect their learning and to provide identified students with Individualized Education Plans (IEPs). The IDEA is currently being reauthorized in Congress. While Rhode Island has the highest national rate of enrollment in special education⁵², it is not known whether this is due to over-identification of children who did not

receive adequate early grade instruction, better identification than in other states, a higher prevalence of disabilities or other factors. According to the 2000 Census, Rhode Island does have one of the highest proportions of children over age 5 with disabilities (after Arkansas and Washington, DC).⁵³ Rhode Island also has lead poisoning rates which are approximately twice the national average and contribute to disability.^{54, 55}

**Children in Special Education, By Disability
Rhode Island, 2002-2003**



- In 2002-2003, in Rhode Island, 33,611 (23%) students ages 3-21 were enrolled in special education.
- Nationally and in Rhode Island, children with learning disabilities constitute the largest category of special education students (46% in Rhode Island).
- There are racial/ethnic differences in Rhode Island in the identification rates of children with disabilities. Black and Hispanic children in the state are disproportionately likely to be identified as mentally retarded and disproportionately unlikely to be identified as speech or hearing impaired or autistic.

Source: Rhode Island Department of Education, Office of Special Education, June 30, 2003. *Special Education Biennial Performance Report, 2000-2001 and Update (2001-2002)*. Rhode Island Department of Elementary and Secondary Education, Office of Special Needs. *Other includes deaf and blind, visually impaired or blind, hearing impaired, multi-handicapped, orthopedically impaired and traumatic brain injury.

SPECIAL EDUCATION TECHNICAL ASSISTANCE RESOURCES

Children with complex or behavioral needs may require a degree of expertise that can be lacking within child care settings and general classrooms, and may result in exclusion, inferior services, low expectations and unnecessarily restrictive placements.

The Rhode Island Technical Assistance Project (RITAP), a collaborative of the Department of Education and Rhode Island College, provides assistance to school districts in areas including autism, traumatic brain injury and behavioral management. www.ritap.org, www.ric.edu/ritap

Another resource is **The Sherlock Center on Disabilities at Rhode Island College** which provides technical assistance, training, and information regarding best practices to schools, families and individuals. www.sherlockcenter.org

The Child Care Support Network is a technical assistance program which assists licensed child care centers with children with special needs.

IMPROVING EDUCATIONAL EXPECTATIONS AND OUTCOMES

*"[W]hile [the special education] label is intended to bring additional supports, it may also bring lowered expectations."*⁵⁶

A child's educational achievement is a predictor of lifelong outcomes. The federal No Child Left Behind Act, signed in 2001, mandates accountability for educational outcomes for all children, including those with special needs, by requiring participation in standardized testing and disaggregated reporting of achievement by students with disabilities. Schools that fail to perform risk loss of federal funding. In January 2003, Rhode Island submitted a plan to the U.S. Department of Education that includes steps for improving data collection and performance outcomes on statewide assessments of children with special needs.⁵⁷

In Rhode Island, as elsewhere, educational and economic outcomes for children with special needs remain significantly below those of all children.⁵⁸ In Rhode Island, the high school dropout rate for students with disabilities is 31% as compared with 12% for all students.⁵⁹ Both high school graduates and dropouts with disabilities are less likely than all Rhode Islanders to work full-time and more likely to have lower wages.⁶⁰ Among individuals ages 18-34 with disabilities, 34% have some college or more as compared with 53% of those without disabilities.⁶¹ Seventeen percent of Rhode Islanders with disabilities (over age 5) are poor compared to 10% overall.⁶²

CHILDREN WITH DISABILITIES STUDY

A 2002 study of children enrolled in special education, commissioned by the Rhode Island Legislature, emphasizes a need to address both the challenges faced by the largest group of children enrolled in special education due to learning disabilities, and to improve outcomes for the smaller number of children with more complex disabilities.

- ***Addressing High-Incidence Learning Disabilities***

The study suggests that many academic difficulties that result in identification of children as learning disabled might be prevented through early identification of reading problems, better teacher training, and intervention programs to address children's needs early, before they become intractable.

- ***Serving Children with Moderate to Severe Needs***

The same study notes that the largest per-pupil expenditures in Rhode Island are for students with mental retardation, multiple disabilities and autism. The most expensive placements are non-public school placements, primarily for children with behavioral or developmental disorders. Outcomes for these children remain poor and require more focused attention.

- ***Achieving Positive Educational and Post-School Outcomes for Children with Disabilities***

Positive outcomes include improved performance on state assessments, improved graduation rates, and improved rates of employment, independent living and participation in post-secondary education. Improving outcomes will require more accurate outcome measurement as well as implementation of proven approaches, such as increased participation in the regular classroom and the general education curriculum, increased involvement in extracurricular school activities and paid employment experiences, and a focus on high quality transition planning.

Source: *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).



PARENT ADVOCACY, SPECIAL EDUCATION FINANCING, AND THE ROLE OF BEST PRACTICE

*“[F]amilies...fear retaliation when they do speak up or complain...[O]nce a child got labeled as ‘special ed’...you are looked at by other members of the community as taking money away from their children...”*⁶⁹

Many parents become skilled advocates for their children’s educational needs. However, the burden of advocacy on families and how it affects outcomes raises several concerns.

- In Rhode Island, the per pupil dollar allotment is the same whether or not a child has special needs and regardless of the extent of those needs. According to the Center for Special Education Finance, in this system of financing, the “fiscal incentive is to provide less service at a lower cost”, increasing the need for advocacy.⁷⁰ While Medical Assistance reimbursement is available to schools for eligible children, it reimburses only a portion of medically-related (not academic) services.

- Even skilled advocates may find it difficult to know what to advocate for in the absence of publicly available information on best practices for teaching children with special needs, especially when the needs are complex.⁷¹
- A system that relies heavily on parent advocacy rather than best practice for serving children with special needs results in a wide variation in services, shortchanging children who lack access to advocacy, sometimes due to barriers such as poverty, low parental education, limited English skills, or complex needs.^{72, 73, 74}

ENGLISH LANGUAGE LEARNERS AND SPECIAL EDUCATION

During the 2001-2002 school year, 10,779 students in Rhode Island were English language learners (receiving English as a second language or bilingual education services). Spanish is the most commonly spoken language (72%) among these students.⁷⁵

Appropriate placement of English language learners in special education is of particular concern: when limited English language skills are confused with learning problems, children may be inappropriately placed in special education classes or, conversely, not assessed for special needs and not provided the special education assistance they may need.⁷⁶

A FOCUS ON THE SPECIAL NEEDS OF CHILDREN IN THE CARE OF THE DEPARTMENT OF CHILDREN, YOUTH AND FAMILIES

Children in out-of-home placement experience developmental, educational, physical, mental and emotional problems at rates significantly above average.⁷⁷ In Rhode Island, children in out-of-home placements must receive a physical evaluation within 60 days of entering care. No similar screening requirement exists for behavioral health or educational needs.⁷⁸

If identified as requiring special education services, children in the custody of DCYF are referred to the Educational Surrogate Parent Program, formerly run by the Office of the Child Advocate and now part of the Sherlock Center on Disabilities at Rhode Island College. In 2002 the program provided advocacy for 1,184 children. Educational stability is an ongoing concern aggravated by transportation barriers: due to changes in living arrangements, children have been known to attend multiple schools in one year, rendering IEP implementation impossible.⁷⁹

INCLUSION: TOWARDS LIFELONG COMMUNITY PARTICIPATION

*"[P]rograms, not children, have to be 'ready for inclusion.'"*⁶³

*"Inclusion... is not simply about 'where'...; it is about quality and relevance."*⁶⁴

The IDEA requires that education for children with special needs be provided in the least restrictive environment appropriate to their needs, an approach known as inclusion and intended to increase expectations and community integration. The IDEA recognizes that some children will need a

specialized environment for at least a portion of their education.⁶⁵ The key is to ensure a continuum of quality placements with adequate flexibility and supports so each child's needs can be addressed in the least restrictive setting.

PROMISING PRACTICES TO PROMOTE INCLUSION

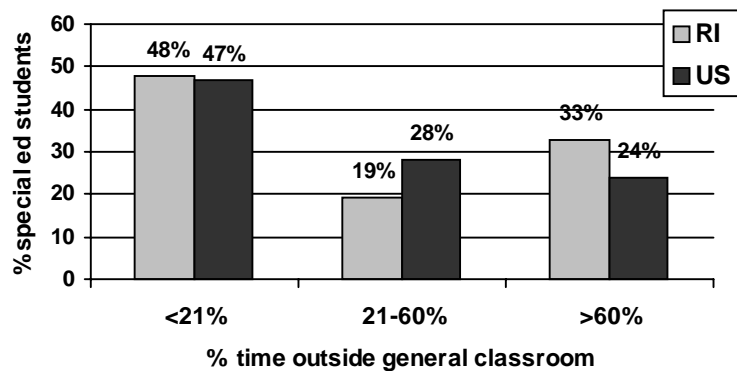
Changing the Paradigm: Sign Language as a Second Language

In an example of promising practices, nine school districts in the St. Louis, Michigan area cooperate to mainstream hearing impaired students in a centrally-located school district that encourages *high rates of sign language competency among the hearing peers* while maintaining a critical mass of hearing impaired students to promote mutual support.⁶⁶

Rethinking Curriculum

Universal Design for Learning (UDL) is a promising approach for teaching, learning and assessment being developed by the National Center for Accessing the General Curriculum funded by the Office of Special Programs in the U.S Department of Education. (www.cast.org/ncac) It draws on brain research to respond to learning differences and strengths in children with and without identified disabilities. UDL is an approach which from the outset creates a curriculum accessible to different learning styles (e.g. visual or auditory) reducing the need for subsequent modifications. It relies on computer technology to individualize teaching materials to make learning engaging and challenging to all students.⁶⁷

**Students with IEPs, Ages 6-21:
Time Outside the General Classroom, RI and U.S.**



- In Rhode Island 48% of special education students spend less than 21% of the school day outside the regular classroom, in keeping with national averages (47%).
- Rhode Island lags behind national inclusion rates for children who may require more assistance: only 19% of Rhode Island students (compared to 28% nationally) fall into the “middle” tier of inclusion (21-60% of their time outside the regular classroom).
- In contrast, 33% of Rhode Island’s special education children spend more than 60% of their time outside the general classroom or are in separate facilities (compared to 24% nationally). Children placed in these restrictive placements include: 92% of children with mental retardation (national rate 56%); 64% of children with emotional disturbance (national rate 51%); and 79% of children with autism (national rate 65%).
- In Rhode Island, Black and Hispanic children are disproportionately likely to spend more than 60% of the school day outside the regular classroom compared with White children.⁶⁸

Source: U.S. Department of Education (2002). *T wenty-fourth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act*. Washington, DC. Data are for 1999-2000.



HEALTH CARE

“The impacts of a child with special health care needs on a parent’s job, finances and time must be recognized... Children with health conditions that are unstable and severe... have needs that are not well met by the present approaches of health plans, government programs, and community agencies.”⁸⁰

According to a recent federal survey, 14.1% of Rhode Island’s children under age 18 (approximately 35,265 children) have special *health* care needs, as compared with 12.8% nationally. Children with special health care needs in this survey were defined as those who have or are at at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.⁸¹ (In contrast, “special needs,” as used throughout this issue brief, refer more broadly to health, education, recreation and other needs.)

Access to health insurance is especially important for children with special health care needs. Rhode Island, along with Vermont and Wisconsin, has the lowest rate of uninsured children (4.3% in 2002) in the country.⁸²

TITLE V PROGRAMS IN RI

A number of projects funded in part with federal Title V dollars and administered by the Department of Health focus on families of children with special health care needs. These include parent consultants stationed in community provider agencies; family service coordinators at primary care sites; assistance for families applying for SSI for their child; and financial assistance for Family Voices of Rhode Island which provides advocacy and support for families raising children with special health care needs.⁸³



CAPACITY GAPS AND WORKFORCE SHORTAGES

While Rhode Island has been very successful in extending health insurance to children, lack of capacity and workforce shortages and other systemic issues continue to limit access to services. Areas of particularly acute and ongoing need include:

- Capacity for in-home services for children who are medically fragile/technology dependent or who have developmental or mental health disorders.⁸⁴
- Capacity in subspecialty pediatric services (e.g. pediatric neurology, psychiatry and psychology).⁸⁵
- Capacity in children’s mental/behavioral health and for children with dual mental/developmental diagnoses; there is a particular shortage of alternatives to crisis or institutional care.⁸⁶
- Family support, training, and respite services.⁸⁷

- Systemic issues such as fragmentation of services, unavailability of services in the child’s community and lack of culturally-competent services.⁸⁸

Capacity problems often result in long waiting times for services, the need to travel long distances for services, and unnecessarily high use of emergency and high-end or hospital care.⁸⁹ For instance, as of October 2003, Home Based Therapeutic Services (HBTS), which serves children with moderate to severe physical, developmental, behavioral or psychiatric conditions, was providing in-home therapy to 450 children but had a waiting list of 275 children.⁹⁰ Likewise, respite services are available to approximately 400 families in Rhode Island and have been identified as a priority need by many families who are unable to obtain them.⁹¹

CEDARR FAMILY CENTERS: COORDINATING SYSTEMS, IDENTIFYING GAPS

Significant fragmentation continues to exist both within service systems, such as health or education, and between agencies. Families of children with chronic needs find it difficult to coordinate their children's educational and health needs, as well as the family's employment needs, the needs of siblings and transportation.

The CEDARR (Comprehensive Evaluation, Diagnosis, Assessment, Referral and Re-evaluation) Family Centers were designed to assist families of children with complex needs through assessment, referral, service coordination, and by identifying gaps in service capacity. There are currently four CEDARR centers in Rhode Island, with an active caseload of 650 children as of the end of June 2003. CEDARRs report continuing difficulty with assisting families with service access and coordination due to a lack of timely access to evaluations, behavioral and mental health services, home-based services and other community based services.⁹²

TRANSITION TO MANAGED CARE

In Rhode Island, many children with special health care needs receive Medical Assistance through fee-for-service arrangements. As of August 14, 2003 children with special health care needs receiving fee-for-service Medical Assistance included: 5,345 enrolled in SSI; 1,252 eligible through the Katie Beckett provision (for children who would otherwise be deemed over-income in order to enable them to be cared for at home); and 2,337 children eligible due to special needs adoptions.⁹³

Pursuant to a recently approved federal waiver, children with special needs currently receiving fee-for-service care can now be transitioned into managed care (RIte Care). Until at least two health plans are ready to participate, enrollment in managed care through Neighborhood Health Plan of Rhode Island (NHPRI) is being offered to families on a voluntary basis.⁹⁴ It is expected that case management services through health plans will improve care coordination for children with complex needs, and that health plans will take an active role in developing capacity where lacking.⁹⁵ Recent studies demonstrate that unless capacity is adequate there is little difference in quality of care or family satisfaction under fee-for-service or managed care.⁹⁶

Other managed care issues of concern to families of children with special needs include: adequate numbers of pediatric-trained professionals in-plan; access to out-of-plan providers; family-centered practice; well-trained gate-keepers, if any; and continuity of care.^{97, 98}

Families of children with special health care needs with access to both private and public health insurance will not be included in the transition to managed care. For these families lack of care coordination and difficulties with coverage for specific services frequently remain barriers to services.⁹⁹

THE IMPACT OF CHILDREN'S SPECIAL NEEDS ON PARENTAL EMPLOYMENT AND WELFARE

Among Rhode Island families of children with special health care needs, 26% report cutting work hours to care for their child and over 10% have been forced to quit work.¹⁰⁰ The impact is likely to be greatest on single parents and on the lowest income workers who are least likely to have sick leave benefits.¹⁰¹

In Rhode Island, more than half (56%) of welfare recipients who were surveyed reported having a child

with a disability. Parents receiving welfare benefits in Rhode Island who have a child with a disability are more likely to report missing work, education or training and are less likely to be employed than other parents. Families with children with developmental disabilities are more likely to remain longer on welfare than other families, are less likely to be employed and more likely to list a variety of barriers to employment such as stress, transportation and personal problems.¹⁰²



ACCESS, COMMUNITY PARTICIPATION, AND TRANSITION TO ADULTHOOD

*“Disability is not a special interest concern; it is a part of the human experience that requires an inclusive social response. The goal is to equalize opportunity....”*¹⁰³

Multiple issues affect the well-being of children with special needs. These include but are not limited to discrimination, transitions, transportation, physical access, and opportunities to participate in community and recreational activities.



THE AMERICANS WITH DISABILITIES ACT (ADA) IN RHODE ISLAND

Adopted in 1990, the ADA prohibits discrimination and ensures equal opportunity for persons with disabilities in state and local government services, public accommodations, commercial facilities, employment, transportation and telecommunications. The U.S. Department of Justice enforces compliance with the ADA.¹⁰⁴

In its 1999 Olmstead decision, the United States Supreme Court determined that unnecessary segregation and institutionalization violates the ADA and “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.... [It] severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.” While Rhode Island is one of only ten states that do not have an official planning body to address the community integra-

tion mandates articulated by the Supreme Court,¹⁰⁵ a number of efforts in Rhode Island do address issues raised in Olmstead. For instance, in 2002, the System of Care Task Force issued a report which includes recommendations to reduce mental health crisis care and hospitalization for children.¹⁰⁶

In Rhode Island, the Governor’s Commission on Disabilities is the coordinator of state compliance with the ADA and other state/federal disability laws. In this capacity the Governor’s Commission activities include: monitoring compliance with court orders; mediating complaints alleging discrimination; providing technical assistance and training; assisting in renovating parks, beaches, trails, state-owned facilities (such as group homes, schools and colleges); engaging in legislative advocacy; and sponsoring an annual public forum.¹⁰⁷

STATE AGENCIES RESPONSIBLE FOR CHILDREN AND FAMILIES WITH SPECIAL NEEDS

**The Rhode Island Department of Children, Youth
and Families**

*Division of Children’s Behavioral Health
Janet Anderson, Assistant Director
(401) 528-3756*

The Rhode Island Department of Health

*Division of Family Health
William Hollinshead, MD, Medical Director
(401) 222-4655*

**The Rhode Island Department of Elementary and
Secondary Education**

*Thomas DiPaola, Director of Special Education
(401) 222-4600, ext. 2301*

The Rhode Island Department of Human Services

*Deborah Florio, Chief, Family Health Systems
(401) 462-0140*

**The Department of Mental Health, Retardation
and Hospitals**

*Sheila Whalen, Chief of Prevention Services
(401) 462-5685*



CHILD CARE

High quality child care is essential for parents to work and provides children with developmental, educational and social opportunities. Yet child care for children with special needs is often unavailable due to a lack of trained providers and supports. In Rhode Island, the Child Care Support Network, managed by the Department of Human Services and the Department of Health, assists licensed child care centers serving children with special needs, through technical assistance and consultation, particularly with regard to mental health and behavioral health. As of October 2003, 22 child care centers and 48 family homes were receiving these supports.¹⁰⁸

In the spring of 2003, the Department of Human Services (DHS) finalized standards for Therapeutic Child and Youth Care (TCYC), which offers additional supports in licensed child care settings for children with moderate to severe physical, behavioral or developmental conditions, to allow participation in integrated child and youth care and promote therapeutic goals. Supports will include clinical oversight, training and paraprofessional assistance.¹⁰⁹



RECREATION/ COMMUNITY SETTINGS

The Personal Assistance Services and Supports (PASS) program is currently being developed by DHS. The program will provide personal attendants to children with special needs, in accordance with individualized plans and will be a consumer-directed mode of service delivery giving families greater choice and control over all aspects of services.¹¹⁰ PASS holds out the possibility for increased community participation by children who require additional levels of facilitation in order to participate in recreational activities, such as summer camps, after-school programs, and sports.

The University of Rhode Island Individualized Sports Skills Program serves children with a variety of physical, developmental, and mental or emotional impairments through individualized aquatics and gymnasium activities provided by supervised student teachers, as part of graded classes in Adapted Athletics. In this way it expands availability of trained staff while providing a valuable recreational and athletic opportunity for children with special needs.¹¹¹



TRANSITION TO ADULTHOOD

Secondary Transition is a mandated part of the IEP process, beginning at age 14, and requires coordination among agencies, employers and independent living programs in order to determine educational, employment and living options that meet individual needs and interests.¹¹²

Research indicates that youth with disabilities who receive mentoring, have work experience and participate in their transition planning

process have much more positive post-school outcomes than those who do not.^{113, 114} The Sherlock Center on Disabilities at Rhode Island College provides statewide technical assistance and training to promote best practices in secondary transitions. Transition Resource Parents at the Rhode Island Parent Information Network, an advocacy and information organization for families of children with special needs, are available to assist parents and school districts with transition planning.¹¹⁵



RECOMMENDATIONS

Prevent Disability

Provide health care and family support services to families at high risk, including preconceptual care, prenatal care, and family support services. Effective health care and family support services can reduce unplanned pregnancies, reduce the use of drugs, alcohol and tobacco, and prevent low birthweight, prematurity, and some congenital diseases and disabilities.

Prevent lead poisoning through education, code enforcement and abatement efforts that increase the supply of lead-safe affordable housing for families with young children.

Promote public education and enforcement of safety standards in order to prevent fetal and infant exposure to other environmental hazards including mercury, pesticides, industrial chemicals, solvents and air pollutants. There is increasing concern in the medical community that such substances may be at least partially responsible for increases in learning disabilities, neurological problems, and other health conditions, such as asthma.

Prevent common childhood injuries through education and regulation. Important prevention strategies focus on fire safety, motor vehicle safety, use of car seats for children, and water safety.

Early Intervention

Ensure that children birth to age 3 enrolled in the Early Intervention program receive services based on the best available research regarding the nature, intensity and duration of services appropriate to their needs. Develop guidelines and outcome measures for particular conditions whenever such research is available. Use the guidelines to inform parents and providers about best practices that can be individualized to the needs of the child and family. Use existing data to describe the nature, intensity and duration of services currently provided by type of disability.

Improve continuity between Early Intervention and preschool. Rhode Island as a state could adopt the approach taken in the Early Intervention Improvement Act, introduced by Congressman Patrick Kennedy at the federal level, by making

services received under Early Intervention the presumptive starting point for services under a child's special education plan.¹¹⁶ Create a uniform transition system statewide and implement fully the state improvement plan goals for preschool transitions, including improved data collection and transition standards.

Develop financing mechanisms to ensure that all children at risk for developmental delay or disability receive intensive and comprehensive services through Early Intervention, Early Head Start or Comprehensive Child Care Services. Document the capacity gap by identifying the number of children at risk and the number enrolled in these comprehensive programs.

Health Care and Family Support

Expand a range of family support and respite services for families of children with disabilities, including those with physical health, mental health and developmental disabilities. One long-term approach is to seek a federal waiver to fund such services through Medical Assistance.

Develop a comprehensive plan to systematically document and address the gaps in services identified by CEDARRs.

Create a specific plan and implementation timetable for resolving longstanding health care workforce and capacity problems, including in-home services, subspecialty pediatric services, and children's mental/behavioral health. Build on existing reports and recommendations such as the System of Care Report. This will require public and private sector leadership, including government, health care providers and health plans, universities, and the business community.

Address the needs of families of children with special health care needs who depend primarily on private insurance to ensure that they receive prompt care authorization and payment as well as assistance with care coordination.



RECOMMENDATIONS

Special Education

Ensure that all schools monitor achievement in the early grades and provide immediate educational support for children who are struggling, as well as prompt special education assessment where appropriate. Special education eligibility criteria should not be narrowed without providing alternative remediation assistance to children who need it.

Monitor special education rates by type of disability, race, ethnicity and language, in order to ensure that minority children and children with limited English proficiency are not erroneously over-identified or under-identified for particular disabilities.

Improve training and in-class supports for general and special education teachers so they have access to a broad range of teaching approaches and have high expectations for children with a range of learning styles or disabilities.

Increase state capacity to provide technical assistance in teaching children with complex special needs and in positive behavior management so as to improve inclusion rates and reduce disproportionate suspensions of children with special needs. Provide incentives to school districts to develop such expertise.

Ensure that best practices for teaching children with particular disabilities are available to parents and educators and serve as foundations for determining services and service levels.

Parental Employment

Consider legislation to provide universal family leave/sick days where not provided by the Family Medical Leave Act. A recent study indicates the cost effectiveness of increased parental leave due to reduced turnover and reduced reliance on public support.¹¹⁷

Ensure that welfare recipients are aware of ill-child work requirement exemptions;

provide specialized case management for parents and children with disabilities or developmental issues that limit school and work opportunities.

Access, Community Participation and Transition to Adulthood

Develop specific plans to increase capacity to meet the need for child care and recreation opportunities for children with special needs by expanding programs such as Therapeutic Child and Youth Care, Personal Assistance Services and Supports, and the Child Care Support Network.

Support positive educational and lifelong outcomes for older youth through increased participation of youth with special needs in the general curriculum and in the general classroom, increased mentoring opportunities, increased youth participation in paid employment experiences and in transition planning.

Increase the involvement of the adult service system in transition planning for youth and increase the extent to which transition services are family and consumer driven.

Children in Out-of-Home Placement

Provide prompt physical, developmental and behavioral health screenings and follow-up including referral to Early Intervention and/or appropriate comprehensive, intensive services for all children in out-of-home placement.

Provide assessments for educational special needs for children entering DCYF custody.

Ensure educational continuity for all children in DCYF care, particularly for those with special needs, by requiring school districts to provide ongoing transportation where needed to ensure such continuity throughout the school year.



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RESOURCES FOR FAMILIES

The Rhode Island Parent Information Network (RIPIN)

Training, information, support and advocacy for families.

(401) 727-4144 or (800) 464-3399

www.ripin.org

Family Voices of Rhode Island

Part of national network supporting families of children with special needs.

See online Family Voices Resource Guide.

(401) 727-4144 or (800) 464-3399

www.ripin.org/fvri.html and www.familyvoices.org

Parent Support Network (PSN)

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

(401) 467-6855 or (800) 483-8844

www.psnri.org

Rhode Island Disability Law Center

Free legal assistance for persons with disabilities.

(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.

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

www.sherlockcenter.org

The Rhode Island Technical Assistance Project (RIDE and RIC)

Technical assistance and professional development to promote improved educational services to all children including those with disabilities.

Judith Saccardo, Director

(401) 456-4600

www.ritap.org

CEDARR Family Centers

Evaluation, case management, referral for children with special needs.

About Families: (401) 365-6855 Family Solutions: (401) 461-4351

Families First: (401) 444-7703 Easter Seals: (401) 284-1000

CEDARR Family Center Resource Guide: www.dhs.state.ri.us

Governor's Commission on Disabilities

Charged with oversight and implementation of the Americans with Disabilities Act and other nondiscrimination laws.

Robert Cooper, Executive Secretary

(401) 462-0100 (401) 462-0101 (TTY)

www.gcd.state.ri.us

Office of the Child Advocate

Protects the civil, legal and special rights of children in DCYF care.

(401) 222-6650

www.child-advocate.state.ri.us/

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