



# Resource Guide for Families of Children with Autism Spectrum Disorders

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OFFICE OF SPECIAL HEALTH CARE NEEDS :: REVISED 2011

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NOTE TO PROFESSIONALS: THIS IS A VALUABLE RESOURCE FOR YOU AS YOU WORK WITH FAMILIES.





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## INTRODUCTION

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Welcome to the Rhode Island Resource Guide for Families of Children with Autism Spectrum Disorders (ASDs). This guide was developed by a committee of experts on ASDs spearheaded by the Rhode Island Department of Health's Office of Special Health Care Needs. Committee members include physicians, members of community service organizations, and families of children with ASDs.

Like many families of children who have been diagnosed with ASDs, you may be feeling overwhelmed. You may be concerned about your child's developmental progress, about whether your child received an appropriate diagnosis, and about what your next steps should be. Help is available.

This Rhode Island Resource Guide provides information for families at different stages of the ASD diagnosis process, to assist them in finding help for their children and family support. Information detailed in this guide includes:

- » The signs and symptoms of ASDs and their effect on child development
- » Adjusting to your child's diagnosis
- » Health coverage assistance
- » Treatments and interventions
- » Educational services
- » Community resources and other family supports

At this point, you may have been to a number of doctors and specialists, seeking diagnosis for your child. You are doing the right thing. Early and appropriate diagnosis can help guide your choices and can lead to better outcomes for your child. Having a specific diagnosis of an ASD can sometimes open doors to services that would otherwise be closed. It is important to remember that only professionals experienced in the diagnosis and management of ASDs can accurately make the diagnosis. Developmental pediatricians, child neurologists, child psychologists, or child psychiatrists usually diagnose ASDs. Other professionals who can help clarify the diagnosis include speech and language pathologists, occupational therapists, physical therapists, geneticists, audiologists, educators, and special educators.

It is not simple to diagnose a child with an ASD, since there are no medical tests to detect it. Doctors may use several medical tests to rule out other conditions and disorders, such as hearing loss, mental retardation, and speech problems. Doctors who specialize in ASDs may use several kinds of tools to determine whether a child has an ASD—from rating scales and

checklists to observing the child's speech and behavior. They also need detailed information about the child's behavior and early development. To make a diagnosis, doctors must see clear evidence of poor social and communication skills and behavioral concerns before age three. Children with ASDs usually have some problems in each area.

Most children with ASDs show signs of their disorders in infancy. Recognition of difficulties with social relationships, communication, and imaginative thought is essential for early diagnosis and intervention. Children with ASDs are usually identified sometime between 18-24 months of age, with the exception of Asperger Disorder, which has a later onset.

For parents/caregivers and family members, learning that your child has an ASD can be very difficult. During the diagnosis process, you may feel isolated and alone. It is important to remember that these feelings are normal. Seeking support from your partner, family, and friends can be helpful. Other families with children with ASDs can also be valuable resources. Additionally, there are many local and national organizations that you can access to learn more about ASDs.

As you learn about ASDs and begin to use the resources and support available to you, you will feel more in control, and your family's life will begin to take shape. The more knowledge that you gain, the more empowered you will become to take on an advocacy role for your child. Remember, you are the most important advocate for your child.



# Welcome to Holland

*by Emily Pearl Kingsley*

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you are going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?" You say, "What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there has been a change in my flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole different language. And you will meet a whole new group of people you never would have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you have been there for a while and catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about the wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

The pain of that will never, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

# Understanding Autism Spectrum Disorders

## DEFINING AUTISM SPECTRUM DISORDERS

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Autism Spectrum Disorders (ASDs) are considered to be neurological disorders, which means that they affect how the brain functions. ASDs can affect each child differently, to different degrees of severity. However, all children with ASDs share difficulties in three areas: social interaction, communication, and repetitive behaviors. Two children with the same disorder can act differently and can have different skills. A child's ability to learn and think can vary from being gifted to being severely challenged. Some children who are mildly affected may show only slight delays in language and more difficulty with social skills. A child with an ASD may have average to above average verbal, memory, or spatial skills, but may find it hard to be imaginative or to participate in activities with his or her friends. Other children may be more severely affected and may need more help with day-to-day activities.

## THE DISORDERS WITHIN THE AUTISM SPECTRUM

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The term Autism Spectrum Disorder is not a specific diagnosis. It is a general term that includes the following diagnoses: Autistic Disorder, Asperger Disorder, and Pervasive Developmental Disorder (including the less common Childhood Disintegrative Disorder and Rett's Disorder).

There are no specific medical tests for diagnosing an ASD. An accurate diagnosis should be based on observation of a child's behaviors, communication, social skills, and developmental level. A diagnosis of an ASD, or any other developmental disability, is based on the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*, published by the American Psychiatric Association. This is the main diagnostic tool used by mental health professionals in the United States. See Appendix C for the diagnostic criteria from the DSM-IV that professionals use to diagnose children with ASDs. At the time of this printing, the DSM-IV is in the process of being revised and will be reprinted in May 2013 as the DSM-V.



*The following are descriptions of each disorder:*

#### **AUTISTIC DISORDER**

Children with Autistic Disorder have trouble forming normal social relationships and communicating with others. They may also have a limited range of activities and interests. Children with Autistic Disorder vary greatly. Autistic Disorder is sometimes referred to as Early Infantile Autism, Childhood Autism, Classic Autism, or Kanner's Autism. Autistic Disorder affects boys more often than girls.

#### **ASPERGER DISORDER**

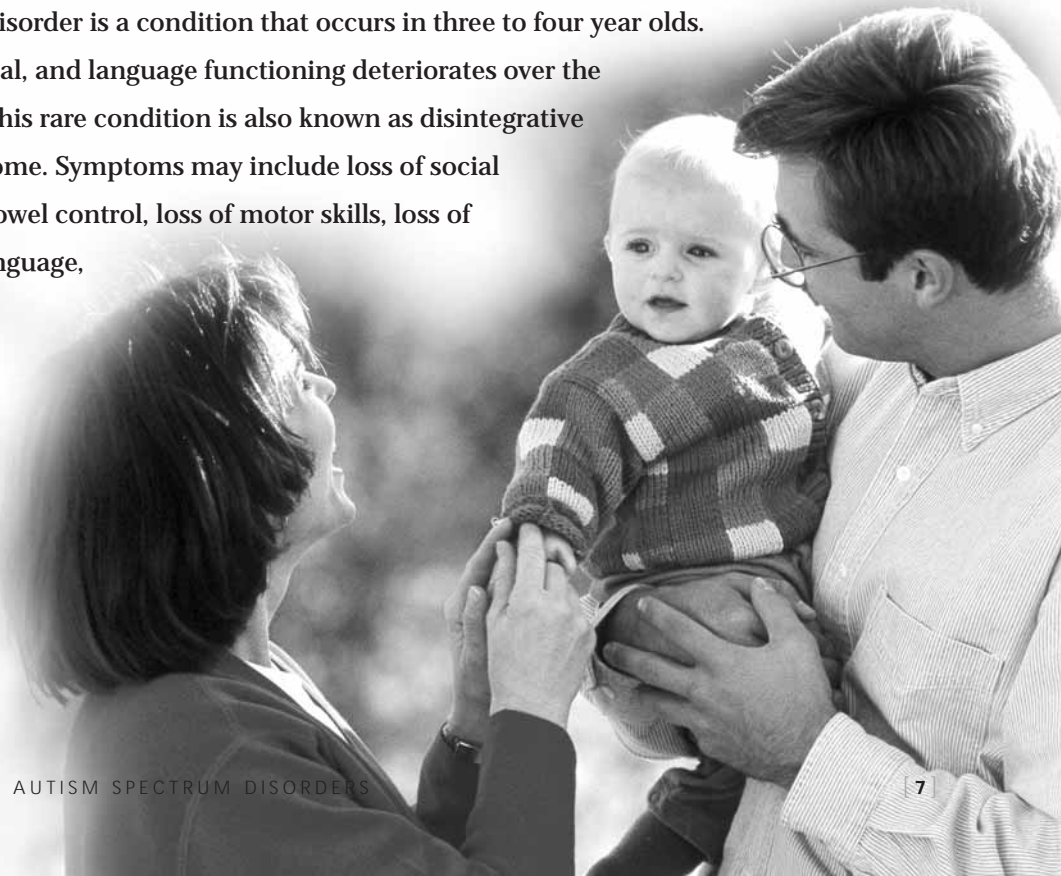
Asperger Disorder (also called "Asperger Syndrome") is a diagnosis that affects more boys than girls. Most children with Asperger's have normal intelligence and early language development. However, they have severely impaired social skills and are unable to communicate effectively with others. Many children with this disorder have poor coordination or repetitive speech, difficulties with reading comprehension, math, or written skills, unusual behaviors or mannerisms, obsession with specific topics, and a lack of common sense.

#### **PERVASIVE DEVELOPMENTAL DISORDER—NOT OTHERWISE SPECIFIED**

Pervasive Development Disorder—Not Otherwise Specified (PDD-NOS) is also called atypical autism. Children with PDD-NOS usually have severe impairment in several areas of development, including social interaction and communication skills. It is a neurological disorder diagnosed when children have many features of autistic disorder but do not meet the full criteria.

#### **CHILDHOOD DISINTEGRATIVE DISORDER**

Childhood Disintegrative Disorder is a condition that occurs in three to four year olds. The child's intellectual, social, and language functioning deteriorates over the course of several months. This rare condition is also known as disintegrative psychosis or Heller's Syndrome. Symptoms may include loss of social skills, loss of bladder and bowel control, loss of motor skills, loss of receptive and expressive language, delay or lack of spoken language, failure to develop peer relationships, lack of play, inability to initiate or sustain a spoken conversation, and impairment in nonverbal behaviors.



# Danny's Story

***The following story by Stephanie, a mother who suspected her son had an ASD, describes the steps she took to get a diagnosis.***

Our son Daniel was born in late July of 2000. Danny, as we call him, grew and developed appropriately. He was chubby and sweet and had an infectious belly laugh...still does. Once he learned to crawl he couldn't wait to tackle climbing. He was also doing the typical babbling and saying DADADA among other jargon. I remember thinking he would be saying DADA very soon. That never happened.

By Danny's first birthday, I became concerned. He seemed to change. He was withdrawn and silent. I could put him to bed and he wouldn't even try to get up. As I started to investigate, I realized he wasn't pointing or waving goodbye. At his 12-month check-up I shared my concerns with his pediatrician and he felt everything was fine. I was still nervous so I contacted Early Intervention. We had an initial visit with Early Intervention and a subsequent evaluation from a speech therapist. We then decided a neurological evaluation was necessary to rule out specific medical conditions. Danny had several tests including an MRI and BEAM (similar to EEG) and every chromosomal test you can imagine. All results were normal.

I had done so much research on my own, but I couldn't decide what the problem was. In my opinion, he presented with many symptoms of autism but I couldn't get professionals to confirm. I joined a local support group when he was 16 months old because I knew other mothers would point me in the right direction. They did. I put his name on a waiting list for speech and occupational therapy at a local hospital. At 18 months, we were able to secure an evaluation. We left with a diagnosis of Mixed Developmental Delay, which was not very helpful.

When Danny was 22 months old, we were finally referred to the Groden Center's Early Intervention program, which proved invaluable. They came to our home one time per week to work with Danny. Danny also attended a playgroup a couple of times a week at the Center. I met people with whom I needed to connect, and things started to come together. We finally received his diagnosis when he was two years old. At 27 months, Danny started an ABA-based home program.

There are so many key elements, but the best advice I could give is to trust your instincts and be involved with your child's therapy. No one wants his or her child to be labeled as anything but perfect. The day you receive a diagnosis might be the worst day of your life but the best day for your child as it opens up doors to services he or she may not otherwise be entitled to. Your child's therapy is your responsibility and being involved, knowing your therapists, and being familiar with your child's programs can only be beneficial to your child. Be sure the people you choose are committed to your child and do everything you can to make them feel welcome in your home. Remember, it's a team effort, and you are a huge part of the team.

It's a very long, difficult road, but we love our son dearly and want him to be the best he can possibly be. First and foremost, he is a little boy. A little boy who works over 40 hours a week and has done so since he was two years old. This is not what we had in mind, but it is what it is and we will continue to do everything in our power to help him.

It's a process that constantly evolves. It requires flexibility and determination.

His triumphs, however small or large, are the highlights of our lives, and his struggles break our hearts. We pray for a cure and hope it comes in time to help Danny. But in the meantime, we love him unconditionally and that is something a diagnosis of any kind will never change.



## RETT'S DISORDER

Rett's Disorder is a genetic brain disorder seen mostly in females (starting between 6 and 18 months of age) and characterized by wringing of hands, slowed brain and head growth, walking abnormalities, seizures, and mental retardation. Symptoms may include toe walking, sleep problems, large or protruding teeth, wide-based walking (walking with feet far apart), and disorganized breathing patterns that occur when awake. A specific genetic test is now available to confirm a diagnosis of Rett's Disorder.

## RELATED CONDITIONS

A number of overlapping conditions may occur with ASDs or, in some cases, may be confused with ASDs. These conditions can be grouped into four categories:

- » Genetic disorders—Angelman Syndrome, Fragile X Syndrome, Prader-Willi Syndrome, and Williams Syndrome;
- » Neurological conditions—Seizure Disorders and Tourette's Syndrome;
- » Psychiatric disorders—Anxiety Disorders, Obsessive Compulsive Disorder, Bipolar Disorder, and Attention Deficit Disorder; and
- » Other learning disabilities and disorders—Attention Deficit Hyperactivity Disorder, Hyperlexia, Mental Retardation, Non-Verbal Learning Disorder, Oppositional Defiant Disorder, and Semantic-Pragmatic Disorder.

Please see the Glossary for a description of these conditions. Most children with ASDs do not have these conditions.

## HOW ASDs AFFECT CHILD DEVELOPMENT

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Families are often the first to notice that their children are not achieving developmental milestones or to observe behaviors that are worrisome. Some families say that their babies seemed different from birth. Other families say that their children seemed to be developing normally before they began to show unusual behaviors or to not develop as expected. A diagnosis of an ASD is based on seeing a child's behavior or symptoms in social relationships, social communication, and imaginative thought. Each symptom can range in severity from mild to severe. The following are possible ways that an ASD may affect child development:

### SOCIAL RELATIONSHIPS

A child may spend more time alone rather than with others, may show little interest in making friends, and may be less responsive to social cues such as eye contact, universal body language, or smiles. Other characteristics may include, but are not limited to:

- » Not wanting to hug or cuddle;
- » Being detached from the feelings of others;
- » Not imitating others;
- » Being unaware of emotions of others; and
- » Lacking spontaneous sharing of interest with others.

#### **SOCIAL COMMUNICATION**

There are reasons for concern when a child does not develop speech or another method of communicating, such as pointing or gesturing. A child may have speech at first and then may lose it. Other symptoms may include:

- » No babbling by one year of age, no single words by 16 months, no two word phrases by 24 months;
- » Not responding to his or her name or verbal cues—may act as if deaf although his or her hearing tests in the normal range;
- » Appearing to not understand simple requests;
- » Difficulty expressing needs and concepts;
- » Repeating words or phrases (called echolalia) instead of using typical language; and
- » Speaking on narrowly-focused topics (e.g., always talking about the same topic, like numbers, letters, or trains).

#### **REPETITIVE BEHAVIORS**

A child may be very focused on one interest or topic. A child may also lack spontaneous or imaginative play, not imitate others' actions, or not initiate or participate in pretend games. Other symptoms may include:

- » Being too attached to objects;
- » Obsessive unusual play with toys or objects (may line them up or spin them);
- » Disliking changes in routine or environment (e.g., a change in daily tasks or schedule, things moved somewhere else); and
- » Unusual body movements (hand flapping or spinning).

#### **SENSORY SENSITIVITY**

For children with ASDs, sensory sensitivity is common. This can result in a child's senses (sight, hearing, touch, smell, or taste) being over- or under-active. Behaviors that may indicate that a child has sensory sensitivity include:

- » Covering ears (sensitivity to the sound of noise);
- » Becoming stiff when held (sensitivity to the feeling of touch);

- » Removing clothes often (sensitivity to the feeling of fabric on the skin);
- » Refusing to eat certain foods (sensitivity to food textures);
- » Putting objects close to nose to smell (sensitivity to smells); and
- » Becoming non-responsive or hyperactive in noisy or bright environments.

#### OTHER CHARACTERISTICS

- » Having frequent temper tantrums for no apparent reason;
- » Showing no fear of danger;
- » Hitting or biting self or others; and
- » Not reacting to pain.

Families can find more information about child developmental milestones on the Centers for Disease Control and Prevention (CDC) website at [www.cdc.gov/actearly](http://www.cdc.gov/actearly)

# Learn the Signs. Act Early.

WWW.CDC.GOV/ACTEARLY • 1-800-CDC-INFO

#### IT'S TIME TO CHANGE HOW WE VIEW A CHILD'S GROWTH.

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As they grow, children are always learning new things. These are just some of the things you should be looking for as your child grows. Because every child develops at his or her own pace, your child may reach these milestones slightly before or after other children the same age. Use this as a guide, and if you have any concerns, talk with your child's doctor or nurse.

#### BY THE END OF 7 MONTHS, MANY CHILDREN ARE ABLE TO:

- » Turn head when name is called
- » Smile back at another person
- » Respond to sound with sounds
- » Enjoy social play (such as peek-a-boo)

#### BY THE END OF 1 YEAR (12 MONTHS), MANY CHILDREN ARE ABLE TO:

- » Use simple gestures (waving "bye-bye")
- » Make sounds such as "ma" and "da"
- » Imitate actions in their play (clap when you clap)
- » Respond when told "no"

**BY THE END OF 1½ YEARS (18 MONTHS), MANY CHILDREN ARE ABLE TO:**

- » Do simple pretend play (“talk” on a toy phone)
- » Point to interesting objects
- » Look at object when you point at it and tell them to “look!”\*
- » Use several single words unprompted

**BY THE END OF 2 YEARS (24 MONTHS), MANY CHILDREN ARE ABLE TO:**

- » Use 2- to 4-word phrases
- » Follow simple instructions
- » Become more interested in other children
- » Point to object or picture when named

**BY THE END OF 3 YEARS (36 MONTHS), MANY CHILDREN ARE ABLE TO:**

- » Show affection for playmates
- » Use 4- to 5-word sentences
- » Imitate adults and playmates (run when other children run)
- » Play make-believe with dolls, animals, and people (“feed” a teddy bear)

**BY THE END OF 4 YEARS (48 MONTHS), MANY CHILDREN ARE ABLE TO:**

- » Use 5- to 6-word sentences
- » Follow 3-step commands (“Get dressed. Comb your hair, and wash your face.”)
- » Cooperate with other children

**QUESTIONS TO ASK YOUR CHILD’S DOCTOR OR NURSE:**

- » What can I do to keep track of my child’s development?
- » What should I do if I’m worried about my child’s progress?
- » Where can I go to get more information?
- » Can you refer me to a specialist for more information?

## DEVELOPMENTAL SCREENING

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Research shows that developmental screening identifies physical, cognitive, and emotional health issues that may otherwise go undetected, providing the opportunity to intervene to correct these problems at the earliest points possible. Early identification of developmental disorders is critical and an integral function of the primary care physician/medical home. The early identification should lead to further developmental and medical evaluation, diagnosis, and treatment.

The American Academy of Pediatrics (AAP) recommends that developmental surveillance be incorporated at every well-child preventive care visit. Developmental surveillance is a continuous process where knowledgeable healthcare professionals identify children who may have developmental problems. The five components of surveillance include eliciting and attending to the parents'/caregivers' concerns about their child's development, documenting and maintaining a developmental history, making accurate observations of the child, identifying risk and protective factors, and maintaining an accurate record of the process and findings. Any concerns raised during surveillance should be promptly addressed with standardized developmental screening tests. The pediatric healthcare professional should also administer screening tests regularly at the 9, 18, and 30-month visits.

Developmental screening is accomplished through the use of a standardized tool that aids the identification of children at risk of developmental disorders. Many screening tools can be completed by parents/caregivers and scored by non-physician personnel; the physician interprets the screening results. Developmental screening identifies areas in which a child's development differs from other same-age children. When screening results cause concern, the child should be referred for developmental and medical evaluations. Early Intervention programs can be very valuable when a child is first identified to be at risk of delayed development, because these programs often provide evaluation services and can offer other services to the child and family even before an evaluation is completed.

## EARLY PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT PROGRAM

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The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program is the child and health component of Medicaid. All children, from birth to age 21, who have medical assistance coverage are eligible to receive preventive, routine healthcare as well as medically necessary specialized care or services. The goal of EPSDT is to identify and treat health conditions early and to promote normal growth and development. EPSDT services, since they include preventive services, are available at a child's regular visit with his or her doctor. In some cases, where special healthcare needs are identified, additional services may be available.



The Rhode Island Department of Human Services has developed two new **EPSDT Periodicity Schedules** for Rhode Island's Medical Assistance Program, one for general health and preventive visits and another for oral health. These new requirements affect children younger than age 21 enrolled in a Rite Care health plan and children enrolled in Medical Assistance Fee-For-Service. The EPSDT Schedule reflects newly released recommendations from the AAP as well as current Rhode Island laws and regulations.

Highlights of the new general health and preventive visits EPSDT requirements include:

- » Three additional well-child visits at 30 months of age, 7 years old, and 9 years old;
- » Developmental screening using a standardized tool at 9 months, 18 months, and 30 months;
- » Autism screening using a standardized tool at 18 and 24 months;
- » Measuring body mass index (BMI) starting at 24 months; and
- » Risk assessment of blood lipids (dyslipidemia), including screening when clinically indicated, starting at 24 months.

The complete EPSDT schedule for general health and preventive visits and oral health can be accessed through the following website: <http://dhs.embolden.com/FamilieswithChildren/HealthMedicalServices/EPSDT/tabid/910/Default.aspx>

## CAUSES OF ASDs

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Researchers are working on finding ways to prevent, diagnose, and treat ASDs and related conditions in children. There are many theories about why more children are being diagnosed with ASDs. The most common theories are that there are both genetic and environmental components and that this may reflect a re-classification of children previously thought to have other diagnoses.

### GENETIC FACTORS

Genetics, or the study of genes, may provide some insight into the causes of ASDs. Our genes are found in nearly every cell of our bodies, and they control the body's growth and functioning. Half of our genes are inherited from our fathers and half from our mothers.

### TALKING WITH A GENETICIST

Talking with a geneticist (a doctor who specializes in genetic conditions) may be recommended to help find the cause of an ASD. The visit usually involves a complete patient history, a family history (known as a pedigree), a complete physical examination, and appropriate blood tests. A family that receives a specific diagnosis can then receive genetic counseling about the chances that an ASD might appear in another family member in the future.

## ENVIRONMENTAL FACTORS

Some people believe ASDs are caused by environmental factors. There are various theories that link environmental factors with ASDs, none of which have been proven by research. These theories include birth trauma, toxins, dietary factors, and immunizations. Without scientific support or professional agreement, the Rhode Island Department of Health does not endorse any of these theories.

Most professionals would agree that:

- » 0.6% (1 in 110) of children are diagnosed with an ASD;
- » Abnormalities of the chromosomes have been found in 6-8% of children with ASDs;
- » When a family has one child with an ASD, the chance it will happen to future children is between 4-8%;
- » Males are affected 3-4 times more frequently than females; and
- » In identical twins, if one is affected, there is a very high chance that the second twin will be affected as well.

Most children with ASDs (90–95%) have “idiopathic” ASDs, meaning that the cause is still unknown. Researchers are working hard to identify the genes associated with idiopathic ASDs. The other 5–10% of children have “secondary” ASDs, which means that there is a known cause.

## MORE ABOUT ASDs

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### THE ORIGIN OF THE TERM “AUTISM”

The terms “autism” and “autistic” come from the Greek work “autos,” meaning self, and were first used by the psychiatrist, Eugene Bleuler, in 1911. Later, in 1943, Leo Kanner, an Austrian psychiatrist at John Hopkins University, again used the term “autism” to describe children with specific behaviors he identified as a neurological condition. Around the same time, in 1944, an Austrian pediatrician in Vienna named Hans Asperger, who was studying children with similar behaviors, also used the description of “autistic.” Both doctors associated the term “autism” with specific features seen in children in the areas of communication, social interaction, and behaviors. Since then, doctors have learned much more about autism’s wide spectrum of behaviors and dispelled the many myths associated with this disorder.

## COMMON MYTHS ABOUT ASDs

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### MYTH: INSIDE EVERY CHILD WITH AN ASD IS A GENIUS.

Famous people including Ludwig Van Beethoven, Isaac Newton, and Albert Einstein have been identified as possibly having had ASDs. Although it is true that some children with ASDs do have IQ scores at the genius level, most do not. Children with ASDs have a full range of IQ scores, just like typically-developing children.

### MYTH: EVERY CHILD WITH AN ASD HAS A SPECIAL TALENT.

There are children with ASDs who do have a special talent. Most children, however, do not. Many children with ASDs have uneven abilities—they may do well in one area, such as math, but not do as well in another area, such as social communication.

### MYTH: CHILDREN WITH ASDs DO NOT HAVE EMOTIONS AND ARE NOT ABLE TO FORM ATTACHMENTS WITH OTHERS.

Children with ASDs do have feelings, but they may express them differently. Research shows that children with ASDs can form attachments to important people in their lives.

### MYTH: CHILDREN WITH ASDs ARE NOT ABLE TO COMMUNICATE.

Many children with ASDs have language skills. Others can learn to communicate through the use of gestures, picture exchange, sign language, spoken language, and computer technology. (See Section 4 for more information about these interventions.)

### MYTH: CHILDREN WHO HAVE ASDs DON'T MAKE EYE CONTACT.

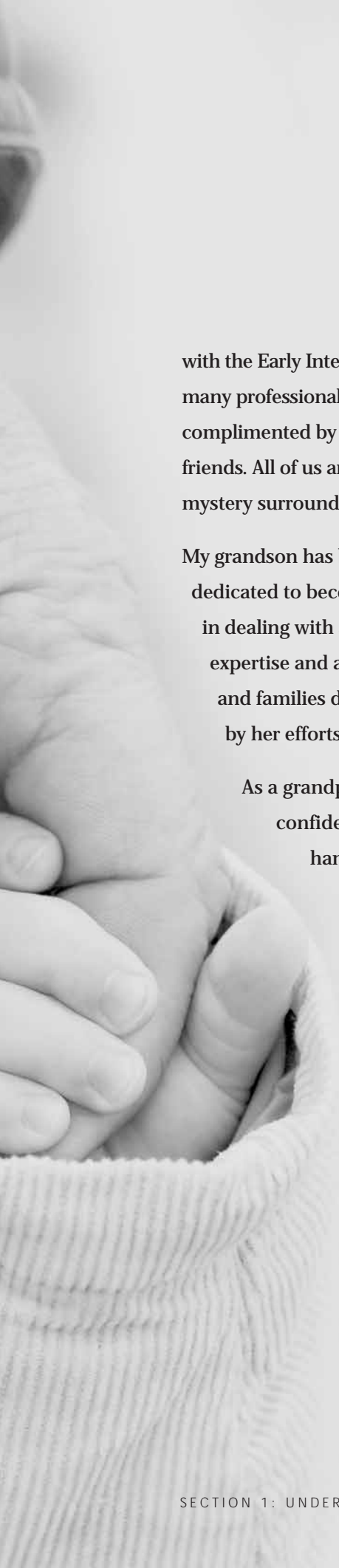
Many children who have ASDs do make eye contact. Eye contact can also be taught to children who have difficulty looking at another person's face.

# A Grandparent's Perspective

A black and white photograph of a hand holding a small basket of eggs. The hand is positioned in the upper right quadrant, with the fingers gently gripping the rim of a small, light-colored woven basket. The basket is filled with several white eggs. The background is a plain, light color, and the overall composition is simple and focused on the act of holding the basket.

Autism—just the word brings anxiety and fear with stereotypical thoughts of a mute child beyond human contact in a world of his own, or a “Rain Man” type autistic savant with amazing powers in some areas but woeful inadequacies in most other aspects of life. A diagnosis brings more questions than answers and eventually an awareness of the broad spectrum involved. One fact that has recently received national media attention is that about 1 in 110 children have autism. It is an equal opportunity attacker affecting all socio-economic levels.

My heartfelt wish is that my seven grandchildren will experience lives full of love, faith, hope, and fulfillment. I bring many years as an early childhood educator to my role as a grandparent. In my profession, I frequently advised families to have children tested and evaluated after noticing early signs of something out-of-sync developmentally. Regarding my own grandson, my previous professional experience and intuition seemed to evaporate. I was in denial of the “red flags” indicating a problem. Fortunately that period of denial was short-lived. I soon realized that my darling grandson, like all children who manifest early warning signs, required testing, evaluation and a team of experts to address his specific needs. Fortunately, my grandson has benefited from the efforts of dedicated medical and educational professionals starting



with the Early Intervention program. The work of the many professionals in my grandson's life has been complimented by the love and support of family and friends. All of us are working to unravel some of the mystery surrounding the depth and breadth of autism.

My grandson has been blessed with a mother dedicated to becoming as knowledgeable as possible in dealing with autism. As a result of her research, expertise and ability, she has become a tireless advocate for her son's needs and those of other children and families dealing with the frustration and challenges in their daily lives. Our family is inspired by her efforts.

As a grandparent, I continue to learn as much as I can about autism. In spite of my fear, I am confident that we will find answers to the questions. Increased public awareness, first-hand experiences, and the heroic efforts of all who have helped my grandson inspire hope for the future.

In the past few years, I have witnessed amazing growth, emotionally, socially, and cognitively in my grandson. His empathy towards others, his eye contact, his ability to spell difficult words, his sense of humor, his interest and ability in reciprocal play, and asking for another kiss and hug rather than resisting physical contact are some of the many little miracles offering hope for his future. How fortunate I am to be the grandparent of a dear child full of potential, mystery, a very different way of looking at the world and such a beautiful smile!

#### RESOURCES TO SUPPORT GRANDPARENTS

The Autism Project and Meeting Street have added programming around supporting grandparents. Please see the Community Resources and Websites section for contact information.

# Adjusting to Your Child's Diagnosis

Families often spend the time before getting their children's diagnoses walking an emotional tightrope between hope and despair—wanting to believe that their children's development is typical but feeling that something does not seem right. Learning that your child has an ASD is difficult to accept. It is perfectly normal for you to grieve for your child and for yourself. The dream of having a “perfect” child seems lost, and you are not sure of your child's and family's future. It is hard to accept that your child is not doing the same things or reaching the same milestones as typically-developing children. But it is important to remember that your child is still the same child that he or she was before receiving his or her diagnosis. Your child still loves you and needs you now more than ever.

## DON'T OVERWHELM YOURSELF WITH INFORMATION

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Many families of children with ASDs have said to not collect too much information about ASDs too early after receiving the diagnosis. While you should eventually collect all the information you need, don't overwhelm yourself in the beginning.

The Internet can be a good resource for information; however, keep in mind that not everything on the Internet is reliable or accurate. If you type the word “autism” into a search engine, you may find the volume of information overwhelming and, in many cases, outdated. The websites listed in the Community Resources and Websites section of this guide may be helpful as you begin collecting information.

## CHRONIC SORROW

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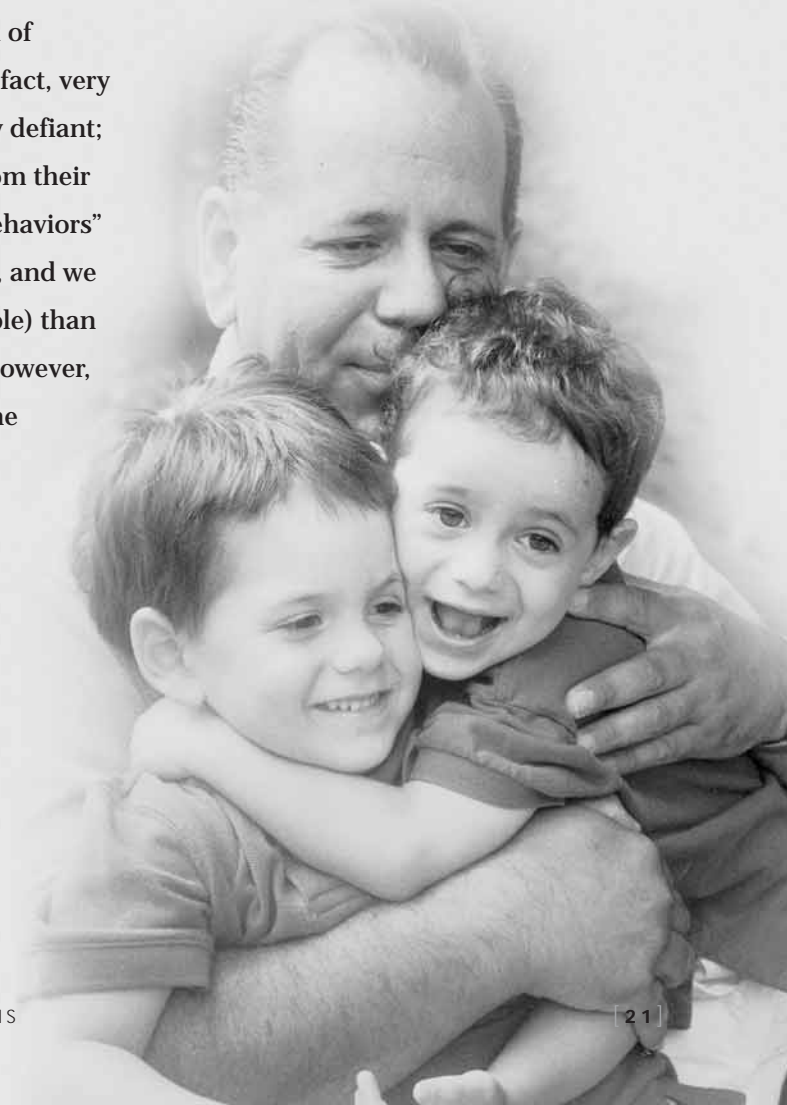
Chronic Sorrow is a term coined by sociologist Simon Olshansky to describe the long-term reaction of families who have a children with disabilities. This pervasive reaction is often not recognized or understood by those around the parents—professionals, family, and friends. These feelings of chronic sorrow are normal and to be expected and accepted, given the life-long implications for the family and child.

# Our Children Have Much to Teach Us

***Learning that your child has an ASD brings up many different emotions for families. For many families, this is a time of uncertainty and stress. Sammi, the mother of a boy with autism, shares some of the feelings that she had during this time:***

One of the hardest things in life is to learn of the troubles or challenges that your children may face as they grow. Whether they are physically, emotionally, or neurologically impaired (or perhaps all three), we too suffer with our children.

One of the most important things that we must do is not only see their disability. Autism, in itself, is actually invisible most of the time. Our children do not look different; however, after a short period of observation, it becomes apparent that they are, in fact, very different. They are not badly behaved, nor are they defiant; their disability and their frustrations that result from their inability to communicate are what cause these “behaviors” to surface. Our children can feel love and be loved, and we MUST love them...more unconditionally (if possible) than others. Perhaps we did nothing to deserve them; however, we have been chosen to raise them. We will become better families—better people—because of them. We will acquire a new tolerance for those with difficulties and disabilities; we will be more sensitive to those who struggle, whom we may not have noticed otherwise. We will stop to lend a hand, for we know that our children may need a random act of kindness bestowed upon them at one time or another.



Many factors can affect the intensity and exhibition of chronic sorrow: the parent/caregiver's personality, the severity of the disability, the nature of the disability, and the adequacy of support and services provided. Chronic sorrow does not mean that the families don't love or feel pride in their children. These feelings, and many other feelings, exist alongside the sadness. It is as if many threads are woven side-by-side, bright and dark, in the fabric of the parents/caregivers' lives. They co-exist; they do not blend into one color or feeling.

Because ours is such a "can do" society, there is pressure on families to quickly put their feelings of sadness away or deny them. Families are told to "think positively" and to "get on with your lives." They are told that God has "selected" them to receive this special child because they are such strong people. These kinds of comments, while well meant, deny the validity of parental long-term grieving. The discomfort of observing pain in those we care about can be part of the reason that others make such comments.

Grieving is a process that takes time, often years. However, there are ways to support the process of grieving. Most families find support in communities of people who understand their experiences because they too, have lived them. It is lonely to be the only family on the block with a child with a disability. Being part of a support group or organization helps to combat feelings of isolation. Engaging in personal activities that do not center on the family member with a disability can help increase feelings of competence and self-worth. Counseling, especially at times of significant milestones, can be useful.

Chronic sorrow becomes a permanent part of the personality structure of most families that have children with disabilities. It's a normal response. Its thread narrows and widens depending on life situations; most often, it is accepted with courage. And, although permanent, it is not the dominant force in interactions with their children. The dominant forces are love and feelings of connectedness to them. More information on this topic can be found online at [leejagers.wordpress.com/2006/04/26/chronic-sorrow](http://leejagers.wordpress.com/2006/04/26/chronic-sorrow)

## THE FIVE STAGES OF GRIEF

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Many families of children who have been diagnosed with ASDs will never forget how it felt when they heard the words, "Your child has an Autism Spectrum Disorder." At first, the diagnosis may not seem believable. Families grieve in different ways. Some families hold everything inside, and others look for support. There is no right or wrong way to grieve. Some family members say that the grief they felt after they got their child's diagnosis was like the grief of losing a loved one. Many families talk about experiencing a rollercoaster of emotions, such as disbelief, shock, relief, denial, sadness, fear, and anger. Many families also expressed feeling overwhelmed and powerless. They had a million questions about how to help their children, but they did not know where to turn for the answers. ASD is a mystery, and it is natural to feel fear and uncertainty.



# Nathan's Story

***The following story written by a grandfather tells of the many challenges that faced his daughter's family faced when his grandson, Nathan, was diagnosed with an ASD.***

My grandson Nathan was less than a year old when I began to suspect he had developmental challenges. He seemed to be in his own world, unable to interact with me at almost any level. There was no discernible recognition of me when I visited and no visible joy or interest in the toys and games I brought as gifts. Thus, the diagnosis of his being on the autistic spectrum was not a surprise. The diagnosis, however anticipated, was still an event filled with dismay and questions, questions, questions. What was his potential? Would he ever talk? Could he ever be mainstreamed? How would this affect my daughter and her family? Could they handle the enormous pressures and demands? What would happen to Nathan after I was gone and his parents were no longer living?

For all of the articles and on-line research, the thousands of paragraphs and millions of words written about autism, my questions could not be answered. Everyone in the family was "at sea." Feelings were raw and emotions high. Some days, it felt as if we were in mourning. Now, it is almost 3 years after the diagnosis and the turmoil that followed.

My daughter and son-in-law have risen to the challenge far better than I could have ever dreamed. They sought good advice. They worked tirelessly to get Nathan the services, therapy and help he needs to fulfill his potential. They taught all of us to deal with the realities and to hope for the best. And Nathan is responding to the help he is getting. He knows who I am; he can say, "grandpa;" he plays with the toys I bring and takes joy in being a child. Each small victory against this disorder brings him closer to his family and his family closer to him and to each other.



As a child with an ASD develops, family members cycle through the different stages of grief, or they are at different stages of grief at different times. Each birthday, family gathering, or holiday may bring up feelings of anger, guilt, and sadness when you see the differences between your child and other children. Many families express that they feel like their worlds have shattered or that their worlds have come to an end. But in time, they may see that it is not the end. It is just different.

All these emotions are normal. Below is Elizabeth Kubler-Ross' (*On Grief and Grieving*, Scribner, NY, 2005) description of the five stages of grief: denial, anger or resentment, bargaining, depression, and finally acceptance.

### *Denial*

In this stage, the family may react with shock and may not believe the diagnosis. Many parents/caregivers may think: "Not my child, the doctors are wrong;" "My child didn't know the people who tested him;" or "My child will outgrow it when he is older." Denial is a common reaction to life-changing news, and it is actually a healthy response that helps a person take in bad news and find a way to cope with it.

### *Anger or Resentment*

Parents/caregivers in this stage may question why this is happening to their child. They may direct their anger at the doctor, at other professionals, or at a higher power (if they have certain religious beliefs). Some families may even be angry with themselves. They may feel guilty that, somehow, they were responsible for the diagnosis. It is important to understand that these feelings and thoughts are common, and they are an important step in the grieving process.

### *Bargaining*

In this stage, families may bargain with themselves or a higher power (if they have certain religious beliefs). They may think: "I will give or do such and such if my child's condition improves." At this stage, the family is beginning to see that their child has an ASD and is trying to find a way to cope with the information.

### *Depression*

The family in this stage is beginning to understand that the diagnosis is not going away, and they can begin to admit it to themselves. Admitting that



# Walk With Me...

*Written by Sally Meyer, 1999*

*Walk in my shoes for one single day.  
Then you will see why I need to pray.  
Come live in my home for a week or two,  
And then remember I am just like you.  
I didn't ask for the things I was given.  
I didn't choose this road I have taken.  
Walk with me hand in hand,  
And then perhaps you will understand.*

*I am really not complaining about the stress in my life,  
I know that we all have strife.  
But walk with me, when you think I am wrong,  
Walk with me and you'll start to belong.*

*Embrace my sorrows, like they are your own,  
And then you will know me and see I have grown.*

*The journey I take is different from yours—  
My life took one of those unexpected detours.  
But this road that I travel is not really so long,  
If the people who watch me will join my song.  
Listen to my footsteps and watch as I dance,  
And then you will know me and give me a chance.*

*Take heart and remember it can happen to you,  
Who knows where my pathway will cross over to you?  
So speak to me softly if you can understand—  
Remember I once stood where you stand.  
And walk with me gently when the day is at end,  
And then I will call you my friend.*

their child has a life-long disability can make people feel very strong emotions, such as sadness, fear, and loss. It is important to recognize that these feelings are completely normal, and expressing them is a part of the grieving process.

## *Acceptance*

This is the last stage in the grieving process. Some families will arrive at this stage earlier or later than others. Accepting your child for who he or she is, and maybe more importantly, for who he or she is not, is difficult. It is important to recognize how difficult acceptance can be and to remember that the family is grieving for their lost child. It is important for the family to remember during the acceptance process that they are not alone.

## **BE YOUR CHILD'S NUMBER ONE ADVOCATE**

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Being a parent or guardian is the most important job anyone could have. All children are dependent on their caregivers for everything. As a parent or guardian, you serve as your child's number one role model. The activities and experiences you expose your child to depend on the level of effort you put into your job as a primary caregiver.

Parenting a child with an ASD is very challenging. Your child needs constant therapies and services other children do not. It is your job to find those services, to coordinate them, and to

monitor how they are working. Many families of children with ASDs find that their life's mission is to help their children reach their full potential. They rise to the challenge and find that making sure that their children get the best care and support possible is very rewarding. As you begin your journey as a caregiver of a child with an ASD, remember that you and your child are a team, and you are his or her number one advocate.

## HOW TO HELP YOUR FAMILY ADJUST

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Many families raising children with ASDs say that they feel stress in different parts of their lives, including family relationships, finances, employment, and mental or physical health. Family participation in activities in the community may also be affected.

When a child has an ASD, the entire family is affected. Day-to-day routines may need to be changed. Life is no longer what the family knew prior to receiving the diagnosis. A grocery store visit, a doctor's appointment, a haircut, a birthday party—these are all activities that families can do with their typically-developing children without worry or cause for adjustment. But for families of children with ASDs, these ordinary events can be very stressful. It is important to remember that your goal is to help your child learn the social skills he or she needs to interact successfully with people in the community.

New experiences are very difficult for children with ASDs, because they like routine, structure, and consistency. A change in routine often creates tension and worry for the child. As difficult as it is, taking small steps and being persistent will eventually lead to the child's adjustment to a new routine.

It is hard for families when their children act differently than what is socially accepted. Families find it hard to deal with their children throwing tantrums out in public, and they are always afraid that this could happen at any moment. Since children with ASDs typically look like other children, some people may make insensitive comments about how your child is behaving. These comments can be very hurtful, and they may make you angry. Some things you can do to cope with this are:

- » Carry a card with the definition of ASDs written on it. Reach into your pocket, don't speak, and show them the card.
- » Talk about your feelings with your partner, neighbor, or a good friend.
- » Call another parent who has a child with an ASD for support.
- » Contact an ASD support group.
- » Talk to one of your child's doctors, therapists, or teachers about your feelings.

# How My Brother With Asperger Affects My Life

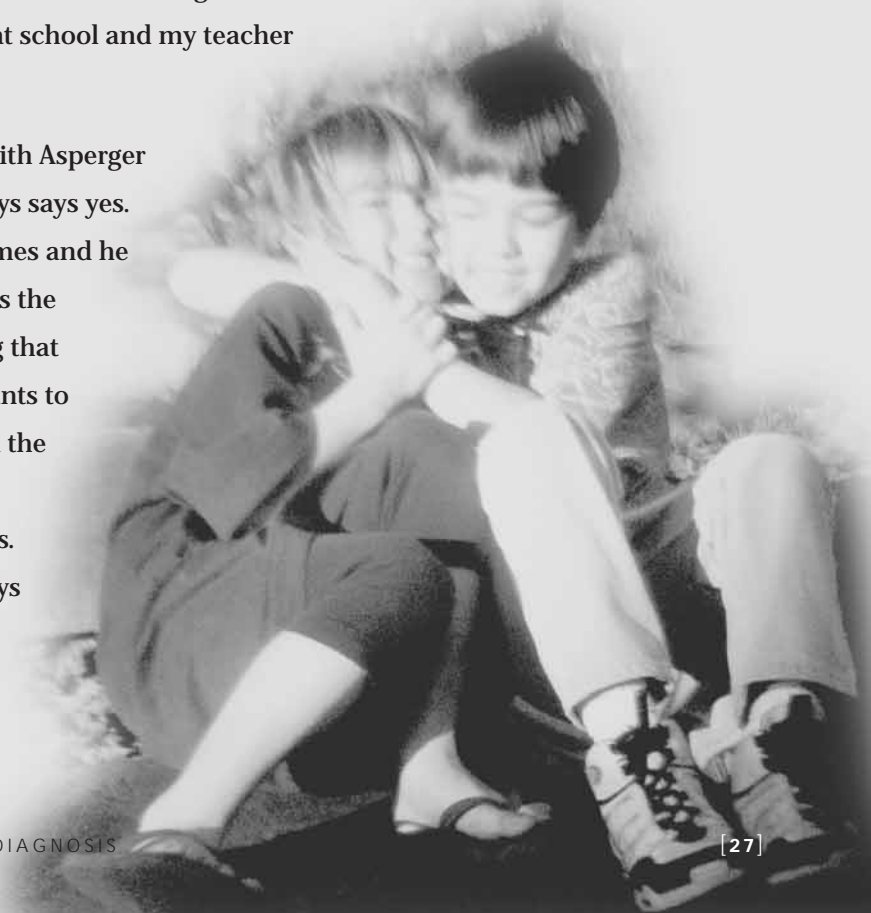
***I hope this article helps kids who have brothers or sisters with special needs know that they are not the only ones with siblings with disabilities. I want to make other kids feel better because I thought I was the only one in the world who had a sibling with special needs.***

I am 10 years old and my brother is 12 years old and has Asperger. Being his brother is both difficult and easy so you could basically say I have mixed emotions.

First I will tell you the difficult things. One of them is that when we go in public my brother usually makes a scene and embarrasses me by acting inappropriately. There is nothing I can do about it. I can't often have friends over because he is mean to them and acts like he is three years old. So some of them think he is stupid and others understand that he has difficulties acting appropriately because he has special needs. He makes me so mad sometimes that my sadness and anger carries over to school, which affects my school work and behavior. He needs so much direction and attention at home that I can't even get a word in.

Consequently, I have to do all my talking at school and my teacher gets mad at me for talking so much.

The good things about having a brother with Asperger is when I ask him to play with me he always says yes. Another great thing is we play pretend games and he has an awesome imagination which makes the games very fun. Sometimes he is so caring that when it's my birthday or Christmas, he wants to get me the best present out of everyone in the family. He is always willing to help me with things I need like homework or video games. Most importantly no matter what, he always says I am his best friend and I feel the same way about him.





#### HELPING SIBLINGS COPE

An ASD is not always easy for siblings to understand. The attention that a child with an ASD needs from caregivers can really impact siblings in the family. To siblings, children with ASDs look as healthy and as “normal” as other kids. This makes it hard for siblings to understand how their brother or sister behaves and why he or she gets special treatment from you and from others. Some siblings may adjust well, while others may feel jealous, embarrassed, or angry. There are many ways that families can help siblings adjust. Being aware of the siblings’ concerns and needs is important. Some ways that you can help siblings cope are:

##### *Teach Siblings Open Communication.*

Most families want their children to talk to them openly. Some siblings are open and honest with their families. They let their families know how having a sibling with an ASD affects their lives. Other siblings may keep their feelings to themselves. Sometimes, this is just a part of their personalities. Other times, siblings may not want to bother their families with their problems, or they may feel guilty about their own feelings. Siblings learn to express their feelings and to share their thoughts by watching how adults express their feelings and how adults deal with emotional situations. Being calm and honest when talking about your own feelings, both when you are happy and upset, is a good model that encourages siblings to talk about their feelings.

Listening calmly to siblings when they talk, without judging what they say, will encourage them to come to you when they have questions or concerns about their brother or sister.

#### *Explain ASDs to Siblings in Simple Terms.*

Siblings need basic information about ASDs. Siblings need to understand that an ASD affects how children learn, how they play, and how they get along with others. It is helpful for siblings to learn that they did not cause an ASD and that they cannot “catch it” or get it later in life. Siblings should also be given basic information about how their brother’s or sister’s condition is being treated. When explaining ASDs to young siblings, families should be calm, should use simple words, and should focus on a few pieces of information at a time.

#### *Focus on Treating Each Child Fairly.*

At some point, most children complain that their parents/caregivers are not being “fair.” Siblings of children with ASDs are more likely to say this when their families let the children get away with something for which the siblings would be punished, or when the siblings cannot do something because of their brothers or sisters. Siblings know that parents/caregivers spend more time with their brothers or sisters, and they are likely to say that this is unfair if families do not seem to take special time alone with the siblings.

It is simply not possible to treat two different children equally. Instead of trying to treat all children equally, try to treat each child fairly. As you will soon learn, fair is not always equal. Try to treat each child according to his or her needs and wants. Make sure all children, including the child with an ASD, are expected to do something to contribute to the family life, like helping around the house and helping each other.

#### *Allow Independence and Individual Time for Siblings.*

All children like to feel that they are unique and loved by their families. It is easy for siblings to feel like they do not get enough attention because of their brother or sister’s special needs. While it is great to do things as a family, it is also normal for siblings to want to have their own friendships and to do activities that interest them. Allow siblings to attend some of their own activities, separate from those of their brothers or sisters. Siblings and parents/caregivers also need their own special time alone together. A special date with a sibling alone to focus on who that child is as an individual is usually as enjoyable for parents/caregivers as it is for siblings. These dates do not have to be long or complicated. Ten minutes of undisturbed special time together each day goes a long way in letting siblings know that they are special too.

#### *Help Siblings Get Support.*

Siblings of children with ASDs may feel that their friends do not understand their situations. Some siblings feel afraid that other children will tease them or that they will not want to be

their friends because of their brothers or sisters. It is helpful for siblings to hear other kids with brothers or sisters with ASDs talk about their good and bad experiences. Meeting other brothers and sisters of children with special needs helps siblings understand that they are not alone—that there are other great kids out there who know exactly how they feel.

Encourage siblings to participate in special sibling activities organized through the child's school or through an ASD organization. SibLink at Hasbro Children's Hospital is a program that was created to meet the needs of brothers and sisters of children with all special healthcare needs, including those with ASDs. SibLink offers services to families on an individual and group basis. All groups are educational, supportive, and fun. For more information, please refer to the Community Resources and Websites section of this guide.

## STEPS TO PROVIDE SAFETY INSIDE AND OUTSIDE THE HOME

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While every child is different, many children with ASDs have no sense of danger and can be impulsive. A child with an ASD may not respond to his or her name when called or may run into traffic even if you scream, "STOP!" This is because he or she may not understand what "STOP" means. Children with ASDs may not understand danger and may often wander off. Because of this, it is very important to make your home and your child's environment safe. These suggestions for making your home a safer place may help to protect your child with an ASD:

- » Put a fence around your backyard and/or your pool.
- » Attach alarms to windows and doors, gates on stairs, guardrails on your child's bed, and childproof latches on cabinets.
- » Make sure that small objects are out of your child's reach and that you know how to give CPR and First Aid.
- » Use audio monitors throughout your home.
- » Make sure that someone is always watching your child.

\* Note: Children with ASDs are often attracted to water sources such as pools, ponds, and lakes. Drowning is the leading cause of death for children with ASDs. As a result, many families register their children in swimming classes for both recreation and safety.

Other steps you can take to increase safety for your child include:

*Put together an informational handout for your local police department and a neighbor(s) whom you can trust.*

Explain your child's condition to them, and give them your handout. Your handout should include your child's picture, weight, height, any distinguishing marks, address, and your home



telephone, cell phone, pagers, and work phone numbers. It should also indicate how your child communicates (e.g., sign language, picture exchange, or non-verbal).

*If your child cannot speak, consider getting an identification bracelet with his or her name, address, and home phone.*

Inform your child's school that he or she will be wearing this bracelet and that it is not to be taken off. More information on identification jewelry can be found on the American Medical ID website at [www.americanmedical-id.com](http://www.americanmedical-id.com).

*Register with the Special Needs Emergency Registry.*

This registry provides Rhode Islanders who require specialized assistance during emergencies with the opportunity to voluntarily provide disability and healthcare information. Information is kept confidential for use by emergency responders, such as town and city police or fire departments.

Website: <https://kidsnet.health.ri.gov/emregistry>

*Provide a Portable Medical Summary to your child's healthcare provider.*

This summary of important pediatric diagnoses, services, and treatments that are critical for a healthcare provider to know to provide continuity of care.

Website: [www.health.ri.gov/forms/medical/PortableSummary.doc](http://www.health.ri.gov/forms/medical/PortableSummary.doc)

*Consider applying for handicapped street signs for your neighborhood.*

You can get these from your town or city administrator. You can also get a handicapped license plate or a placard from the Department of Motor Vehicles.

*Decrease the chance of accidents happening in the home by labeling potentially dangerous items (e.g., the oven, iron, or refrigerator) with signs that say NO or STOP.*

# Steps after Diagnosis

After your child has been diagnosed with an Autism Spectrum Disorder (ASD), some of the first issues or questions you will want to consider include:

1. **ASSISTANCE:** How will I provide for my child's care? What does my insurance cover?

What type of assistance is my family eligible for through state or federal programs?

Where should I start looking?

**First Steps:**

- » Check with your health insurance to see which services are covered.
- » Contact a community family support service (listed in the Community Resources and Websites section) to learn about the different assistance programs that are available and whether your child would qualify to receive these services.
- » Explore Medical Assistance (Medicaid) services.

2. **TREATMENTS AND SERVICES:** Which treatments and services will my child need?

How do I find out what's best for my child? Where do I find these services?

**First Steps:**

- » Talk to your doctor or the diagnosing physician about your child's options.
- » Contact the Rhode Island Early Intervention program (if your child is younger than three years old) and/or a CEDARR Family Center for help determining which treatments and services may be best for your child.

3. **EDUCATION:** What issues do I need to consider in terms of my child's education?

**First Steps:**

- » If your child is younger than age three, enroll your child in the Rhode Island Early Intervention program. Early Intervention can help your child transition to the public school system for special education services (if eligible) or to another appropriate community program/service.
- » If your child is older than age three, contact school officials and formulate a plan with school professionals.

# A Different Kind of Hero

***Janine, a mother of a boy with an ASD, provided a story that her 12-year-old daughter wrote about her brother for an annual contest sponsored by her school.***

Every day he gets up. He has to be helped to the bathroom. He needs to be cleaned and eating breakfast is really hard. He hates to eat; sometimes just smelling food makes him gag. He smells everything. He gets dressed with help, and then they come to our house or he gets on a school bus and he goes with them. They teach him how to walk, how to use a fork and spoon, how to speak and how to look at you when you call his name.

He has no friends, but he is always busy. He hardly talks, but most of the time when the phone rings it is for him. I am talking about my baby brother. He is 3 years old. I am 12. Even though I am older, I look up to him now, and I probably always will. He is my different kind of hero. He has autism.

Every day is a struggle for him to learn how to do the things we do. Like going to the bathroom. Putting on your clothes, eating a bowl of cereal, or just saying good morning. Instead of getting to play with a bunch of kids like other three year olds, he is busy inside classrooms learning how to be a person.

Some people think that a kid with autism has no feelings. Not true. I say that they have too many feelings. With my brother in my life I can now see kids who have the same disability. I see how it is for them. I think about when my brother gets older, and I know he will always be different. I know that he will get laughed at, and I know that he will not have many friends. All I can say is I feel sorry for the people who will never give him a chance to shine. They will be missing out on the greatest thing in the whole world and that is simply... him, my brother with autism.

## MEDICAL ASSISTANCE (MEDICAID)

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If your child has been diagnosed with an ASD, you are probably concerned about handling the financial costs of your child's care. Check with your health insurance carrier to find out which services are covered by your insurance. Additionally, Medical Assistance, also called Medicaid, could be an invaluable resource to you, and it should be one of the first resources that you investigate.

Medical Assistance is a federal and state program that was created in 1956 by Congress under the Social Security Act. Medical Assistance programs are jointly funded by the federal and state governments and are administered by each individual state. In Rhode Island, the Rhode Island Department of Human Services is the state agency responsible for administering the Medicaid Program. Medical Assistance should not be confused with Medicare, which is a federal insurance program. For more information on Medicaid, please visit the United States Department of Health and Human Services website at [www.cms.gov/home/medicaid.asp](http://www.cms.gov/home/medicaid.asp)

Medical Assistance programs pay for services identified in a plan called the State Plan. Within the Medical Assistance program for children birth to 21 years of age is the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program. Under this program, children receive screening and diagnostic services as well as any medically necessary treatments that may not be available under a state's Medical Assistance plan but are allowed under federal Medicaid law. The EPSDT program ensures that Medical Assistance benefits for children are the same across the delivery systems.

Families and children in Rhode Island may be eligible for Medical Assistance by applying for coverage through the following:

- » RIte Care (Rhode Island's Medicaid managed care program)
- » RIte Share (Rhode Island's premium assistance program)
- » Supplemental Security Income (SSI) Program
- » Katie Beckett Eligibility
- » Adoption Subsidy

Descriptions of these programs, including contact information, are found further in this section of the guide (pages 40–42).

**MEDICAL ASSISTANCE APPLICATION ASSISTANCE**

Family Resource Counselors (FRCs) educate families about which types of assistance they might be eligible for and can help them apply for programs. FRCs serve families statewide at no cost to the child or family. The locations are listed below. Please call for appointments.

**COMMUNITY HEALTH CENTERS**

**Blackstone Valley Community Health Centers:**

*Central Falls*

9 Chestnut Street, Central Falls, RI 02863

Phone: (401) 724-7110

Fax: (401) 724-0209

*Pawtucket*

42 Park Place, Pawtucket, RI 02860

Phone: (401) 722-0081

Fax: (401) 728-8730

*Block Island*

6 Payne Road, Box 919, Block Island, RI 02807

Phone: (401) 466-2974

Fax: (401) 466-5476

**Chad Brown:**

285A Chad Brown Street, Providence, RI 02908

Phone: (401) 274-6339 ext. 18

Fax: (401) 831-5953

**Comprehensive Community Action Program (CCAP)/Family Health Service:**

*Cranston*

1090 Cranston Street, Cranston, RI 02920

Phone: (401) 943-1981 ext. 106 or 107

Fax: (401) 943-2846

*Coventry*

191-195 MacArthur Boulevard, Coventry, RI 02816

Phone: (401) 828-5335

Fax: (401) 828-2914

*Warwick*

226 Buttonwoods Avenue, Warwick, RI 02886

Phone: (401) 732-9090

Fax: (401) 732-2790

East Bay Community Action Program (CAP):

*Newport*

18 Broadway, Newport, RI 02840

Phone: (401) 847-7821

Fax: (401) 847-6220

*Riverside*

100 Bullocks Point Avenue, Riverside, RI 02915

Phone: (401) 437-1008

Fax: (401) 433-1598

Providence Community Health Centers:

*Allen Berry*

202 Prairie Avenue, Providence, RI 02905

Phone: (401) 444-0570

Fax: (401) 444-0427

*Capitol Hill*

40 Candace Street, Providence, RI 02908

Phone: (401) 444-0550

Fax: (401) 444-0425

*Central*

239 Cranston Street, Providence, RI 02907

Phone: (401) 444-0580

Fax: (401) 444-0428

*Chafee*

One Warren Way, Providence, RI 02905

Phone: (401) 444-053

Fax: (401) 444-0423

*Olneyville*

100 Curtis Street, Providence, RI 02909

Phone: (401) 444-0540

Fax: (401) 444-0424



**Thundermist:**

*Woonsocket*

450 Clinton Street, Woonsocket, RI 02895

Phone: (401) 767-4100 ext. 3476

Fax: (401) 767-4169

*Wakefield*

1 River Street, Wakefield, RI 02879

Phone: (401) 783-0523 ext. 129

Fax: (401) 782-0859

*West Warwick*

1219 Main Street, West Warwick, RI 02893

Phone: (401) 615-2800 ext. 2103

Fax: (401) 615-2805

**Tri-Town:**

1126 Hartford Avenue, Johnston, RI 02919

Phone: (401) 519-1940, (401) 519-1979, (401) 519-1957

Fax: (401) 351-6613

**WellOne:**

*North Kingstown*

308 Callahan Road, North Kingstown, RI 02852

Phone: (401) 295-9706 ext. 10

Fax: (401) 295-0920

*Pascoag*

36 Bridgeway, Pascoag, RI 02859

Phone: (401) 567-0800

Fax: (401) 567-0900

**Wood River:**

823 Main Street, Hope Valley, RI 02832

Phone: (401) 539-2461 ext. 136 or 137

Fax: (401) 539-2662

## HOSPITALS

### Hasbro Children's Hospital

593 Eddy Street, Providence, RI 02903

Phone: (401) 444-8893

Fax: (401) 444-7297

### Kent Hospital

455 Tollgate Road, Warwick, RI 02886

Phone: (401) 737-7010 ext. 5518, 5433, or 1674

Fax: (401) 736-4602

*(Please ask for a Financial Counselor)*

### Landmark Medical Center

115 Cass Avenue, Woonsocket, RI 02895

Phone: (401) 767-4100 ext. 2447, 2449, or 6636

Fax: (401) 736-1637

*(Please ask for a Public Assistance Advocate)*

### Memorial Hospital of Rhode Island

111 Brewster Street, Pawtucket, RI 02860

Phone: (401) 729-2634

Fax: (401) 729-2156

### Miriam Hospital

164 Summit Avenue, Providence, RI 02906

Phone: (401) 793-2243

Fax: (401) 793-9821

*(Please ask for a Financial Advocate)*

### Newport Hospital

11 Friendship Street, Newport, RI 02840

Phone: (401) 845-1054

Fax: (401) 848-6003

### Rhode Island Hospital

593 Eddy Street, Providence, RI 02903

Phone: (401) 444-7550

Fax: (401) 444-3670

*(Please ask for a Patient Financial Advocate)*



### South County Hospital

100 Kenyon Avenue, Wakefield, RI 02879

Phone: (401) 788-1383 or (401) 782-8035 ext. 12

### St. Joseph Hospital

*Providence Hospital for Specialty Care*

21 Peace Street, Providence, RI 02907

Phone: (401) 456-4072

Fax: (401) 456-4288

*North Providence – Fatima Hospital*

200 High Service Avenue, North Providence, RI 02904

Phone: (401) 456-3924

Fax: (401) 456-3652

### Women and Infants Hospital

101 Dudley Street, Providence, RI 02905

Phone: (401) 274-1100 ext. 1335, 1424, 1419, or 2778

Fax: (401) 453-7536

*(Please ask for a Financial Counselor)*

### COMMUNITY ORGANIZATIONS

#### Progreso Latino

626 Broad Street, Central Falls, RI 02863

Phone: (401) 728-5920 ext. 338

Fax: (401) 724-5550



#### RITE CARE PROGRAM

RIte Care is Rhode Island's Medicaid managed care program that provides eligible families and eligible uninsured pregnant women, families, and children up to 19 years of age with health insurance coverage. Families receive most of their healthcare through one of two participating health plans: Neighborhood Health Plan of Rhode Island or United Healthcare of Rhode Island.

Neighborhood Health Plan of Rhode Island  
299 Promenade Street, Providence, RI 02908  
Phone: (401) 459-6000 or (800) 963-1001  
Fax: (401) 459-6066  
Website: [www.nhpri.org](http://www.nhpri.org)

United Healthcare of Rhode Island  
475 Kilvert Street, Suite 310, Warwick, RI 02886  
Phone: (401) 737-6900  
Website: [www.unitedhealthcare.com](http://www.unitedhealthcare.com)

#### RITE SHARE PROGRAM

RIte Share is a premium assistance program that helps low- and middle-income families obtain health insurance coverage through their employers or their spouses' employers by paying all or part of the employee's share of monthly premiums. Under the RIte Share Program, an individual who is income eligible for Medical Assistance and employed by an employer who offers a RIte Share-approved health plan can enroll in his or her employer's health insurance plan and receive assistance with premiums. The RIte Share Program will also pay all or part of the co-payments associated with the employer's health plan.

For more information about RIte Care or RIte Share, contact:

Rhode Island Department of Human Services  
Center for Child and Family Health  
Hazard Building, Ground Level, 74 West Road Building #74, Cranston, RI 02920  
Information Line: (401) 462-5300 (English or Spanish)  
TTY: (401) 462-3363  
RI Relay: 711  
Website: [www.dhs.ri.gov](http://www.dhs.ri.gov)

#### SUPPLEMENTAL SECURITY INCOME PROGRAM

Supplemental Security Income (SSI) is a federal program that provides health insurance monthly cash payments to individuals, including children (birth to 18 years of age) with physical, developmental, and/or mental impairments that result in “marked and severe functional limitations.” If a child is eligible for SSI benefits in Rhode Island, he or she is also eligible to receive Medical Assistance (see the RIte Care section above for more information). Children younger than the age of 18 with a physical, developmental, and/or mental impairment may be eligible for SSI if their families also qualify based on limited income and resources. After the age of 18, SSI benefits are based only on the income of the individual applying for SSI. For more information, contact:

Social Security Office

380 Westminster Street, Room 318, Providence, RI 02903

Phone: (401) 528-4535 or (800) 772-1213

Fax: (401) 528-4698

Website: [www.ssa.gov](http://www.ssa.gov)

#### KATIE BECKETT ELIGIBILITY

Katie Beckett is a special eligibility process that allows certain children younger than the age of 18 with significant disabling conditions to obtain Rhode Island Medical Assistance coverage. Eligibility is determined by the child’s income and resources (not the family’s) and a “level of care determination.” A level of care determination means that if the child was not living at home with Medical Assistance benefits/coverage, he or she would require care and services in a hospital, skilled nursing facility, or institutional setting. The cost of care provided at home must be less than what Medical Assistance would pay if the child were in a hospital or other institutional setting. For more information, contact:

Rhode Island Department of Human Services

Center for Child and Family Health

Hazard Building, Ground Level, 74 West Road Building #74, Cranston, RI 02920

Phone:

» For help with the application process (Social Caseworker): (401) 462-0760

» For clinical questions (Public Health Nurse): (401) 462-6364

» For general information (Information Line): (401) 462-5300 (English or Spanish)

TTY: (401) 462-3363

RI Relay: 711

Website: [www.dhs.ri.gov](http://www.dhs.ri.gov)

#### ADOPTION SUBSIDY

Adopted children may qualify for an adoption subsidy, which includes a stipend and Medical Assistance. The Adoption Subsidy Program is administered through the Department of Children, Youth, and Families. For more information, contact:

Rhode Island Department of Children, Youth, and Families  
Adoption Services Unit, 101 Friendship Street, Providence, RI 02903  
Phone: (401) 254-7021  
Website: [www.dcyf.ri.gov](http://www.dcyf.ri.gov)

#### MANAGED CARE FOR CHILDREN WITH SPECIAL HEALTHCARE NEEDS

Neighborhood Health Plan of Rhode Island and United Healthcare of Rhode Island both offer a specialized care management program for children with special healthcare needs. Children with special healthcare needs include children who are eligible for Rhode Island Medical Assistance through SSI, Katie Beckett, or Adoption Subsidy. Eligibility for enrollment is determined by the Department of Human Services. The specialized managed care program provides an assigned case manager who works with the member and their family to make sure that all of the member's healthcare needs are met.

Neighborhood Health Plan of Rhode Island  
299 Promenade Street  
Providence, RI 02908  
Phone (401) 459-6000 or (800) 963-1001  
Fax: (401) 459-6066  
Website: [www.nhpri.org](http://www.nhpri.org)

United Healthcare of Rhode Island  
475 Kilvert Street, Suite 310, Warwick, RI 02886  
Phone: (401) 737-6900  
Website: [www.unitedhealthcare.com](http://www.unitedhealthcare.com)

## SERVICES

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### RHODE ISLAND EARLY INTERVENTION PROGRAM

Each state is mandated to provide an Early Intervention (EI) program for children (from birth to three years of age) with developmental delays in accordance with a federal law entitled the Individuals with Disabilities Education Act (IDEA). In Rhode Island, the Rhode Island Department of Human Services administers the EI program.

EI is a family-centered program that promotes the growth and development of infants and toddlers with developmental challenges. EI serves all eligible children (from birth to three years of age) and their families, regardless of income or health insurance coverage. All EI sites provide services to children with ASDs and their families. Services are individualized to support and assist families in meeting the goals that they have for their children.

Referrals for a child who has an ASD or symptoms of an ASD can be made directly to EI programs by family members, guardians, primary care physicians, and community agencies for infant and toddler screening, evaluation, and assessment to determine eligibility for services. When a child is referred to EI, eligibility is determined through an evaluation and assessment performed by the EI program. Some children are eligible based on their diagnoses. This includes children with an ASD diagnosis. The purpose of the evaluation and assessment process includes not only eligibility determination, but also information gathering for planning purposes and answering the family's questions regarding their child's development.

#### *Individualized Family Service Plan*

After a child is determined eligible for EI, the EI staff and the family design a plan called the Individualized Family Service Plan (IFSP). This plan outlines the child's strengths and needs and documents the family's concerns and priorities. It is developed based on the information gathered from an evaluation or assessment and direct input from the family. The IFSP focuses on the goals or outcomes the team, including the family, identifies for each individual child. The team then talks about the strategies and supports that can be used to meet the desired outcomes or goals in the IFSP. Strategies and supports are transdisciplinary, meaning they involve professionals with various backgrounds working together with the family toward the same outcomes. The plan is developed so that it can be implemented in the child's "natural environment," or where the child spends the majority of his or her day. "Daily routines," like playtime and mealtime, are when most of the strategies take place, making it easier for the family to carry out the plan in between visits from EI. The IFSP is reviewed every six months and can be changed at any time.

### *Program Model*

A key component of the EI model is the teaming of families and professionals. Each family participating in EI is assigned a Service Coordinator. The Service Coordinator is responsible for coordinating the services in the IFSP. The Service Coordinator also serves as the single point of contact for the family to obtain services and to provide assistance as needed.

EI services are provided in natural environments to increase the child's participation in typical family and community activities and routines. Parents and caregivers are involved in actual "hands-on" activities throughout the day, with the service providers acting as consultants, teachers, and coaches. Natural environments are the day-to-day settings, routines, and activities in which a child would engage if he or she had no disability and where young children learn best.

### *Family Support Staff*

Every EI program has at least one Family Support Specialist (previously known as a Parent Consultant) available to help families participating in the program. Family Support Specialists have had personal experience with EI; they can assist families with system navigation and can provide them with resources, support, and connections to other families. Family Support Specialists work closely with the EI staff and provide the "family perspective." Their role becomes especially important to many families as they prepare to transition out of EI.

### *Family Rights*

Families of children in EI have certain rights that are specified by state and federal laws. These rights are known as "procedural safeguards." Procedural safeguards are intended to encourage the family to play an active role in the decision-making process regarding EI services and to provide opportunities for the family to fully inform the EI team about their views and priorities. All families in EI receive the "Family Rights" booklet, which explains the procedural safeguards in detail.

### *Rhode Island Early Intervention Certified Providers*

Anyone, including families, can make a referral to the EI program. For more information on which Early Intervention programs serve your city or town, please call the Rhode Island Parent Information Network at (401) 270-0101. For a full list of EI certified providers, please see the Community Resources and Websites section of this guide.

### *The Groden Early Intervention Center*

Children in EI that have characteristics of autism, other communication or behavioral disorders, or a diagnosis of an ASD may be referred to The Groden Center's Early Intervention program. The Groden Center EI program works in collaboration with the ten full-service, certified EI providers in the state. For a child to participate in the Groden EI program, he or she must be enrolled in one of the other EI programs. Together, the programs provide a range of services to address the goals the family has identified on the IFSP.

#### TRANSITION FROM EARLY INTERVENTION

Rhode Island's statewide EI system provides services to families with children younger than three years old who have been diagnosed with, or are at risk for, developmental delay. The individual school district, often referred to as the Local Education Agency (LEA), is responsible for the education of children with special needs from age 3 to 21. Families are guided through the transition process by their service coordinator and family support staff, who have personally been through this process. It is important to remember that the family is involved in every step of the transition process.

When a child in EI turns 28 months old, the family will be asked to sign a release allowing a referral to the local school district. The family's service coordinator will schedule a transition conference meeting with the family and the LEA, to be held around the time the child is 30 months old. At the transition meeting, the team will share information about the child, plan for next steps, and write an Individual Transition Plan. If more information is needed, a plan will be made for who is responsible. Additional evaluations can be scheduled if needed. Children who turn three during the summer months will begin their transition process early so that plans can be finalized before summer break.

Not every child graduating from EI will be found eligible for services through the school system; however, each of these families should have a transition planning conference. All families should also be informed about Child Outreach screening programs and other resources in their community.

Between 30-35 months of age, the LEA will convene an Eligibility Meeting. The Evaluation Team, including the parent(s)/caregiver(s), will decide whether the child is eligible for special education.

If the child is eligible, an Individualized Education Program (IEP) Meeting will be scheduled. If the child is not eligible for special education, the transition team will help the family locate appropriate community resources that may continue to support the child's development as stated in the child's Transition Plan.

At the IEP meeting, the team, including the parent(s)/caregiver(s), develops an IEP for the child. The team will determine the services and placement (if appropriate) where the child will receive those services. The team will complete referrals to other community resources, and the child will be discharged from EI.

All families of children eligible for Medical Assistance should be informed about CEDARR Family Centers at an appropriate time during their experience in EI. With a parent's permission, the EI Service Coordinator can initiate a referral for the child to CEDARR. A child does not need to be in special education to access CEDARR services.

A number of publications have been written to guide families through the transition process. These are provided to families by their Service Coordinators and are available on the Paul V. Sherlock Center on Disabilities at Rhode Island College's website, [www.ric.edu/sherlockcenter/ei.html](http://www.ric.edu/sherlockcenter/ei.html)

#### **CEDARR FAMILY CENTERS**

CEDARR stands for Comprehensive Evaluation, Diagnosis, Assessment, Referral, and Re-evaluation. A CEDARR Family Center is place where families get help and support for children with special needs. Through a CEDARR Family Center, a family can learn more about their child's disability/condition and how to address their child's needs, find community resources, get information on a range of services/treatment options, and connect with other families.

To be eligible for CEDARR Family Center services, a child must be eligible for Medical Assistance, younger than 21 years old, a Rhode Island resident, living at home, and diagnosed with a disabling or chronic condition that is cognitive, physical, developmental, and/or psychiatric. The following services may be available for eligible children and youth with special healthcare needs serviced through CEDARR Family Centers: Home Based Therapeutic Services (HBTS), Personal Assistance Services and Supports (PASS), Kids Connect, and Respite. There are four CEDARR Family Centers that serve families statewide. Please see the Community Resources and Websites section of this guide for contact information.



## OTHER RESOURCES

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As you research treatments, education, and medical services for your child with an ASD, you may find yourself needing other services and support. You don't have to face your child's ASD diagnosis alone. There are many community resources available in Rhode Island for children with ASD and their families. Section 6 of this manual contains an extensive list of the programs and resources in Rhode Island that are dedicated to providing services for children with ASDs, including:

- » Education
- » Evaluation, Assessment, and Diagnosis
- » Legal Assistance/Advocacy
- » Service Coordination/Resource Centers
- » Support for Parents/Caregivers and Families
- » Therapeutic Recreation
- » Transportation Services
- » Treatment and Therapeutic Services
- » Vocational Assistance/Transitional Services

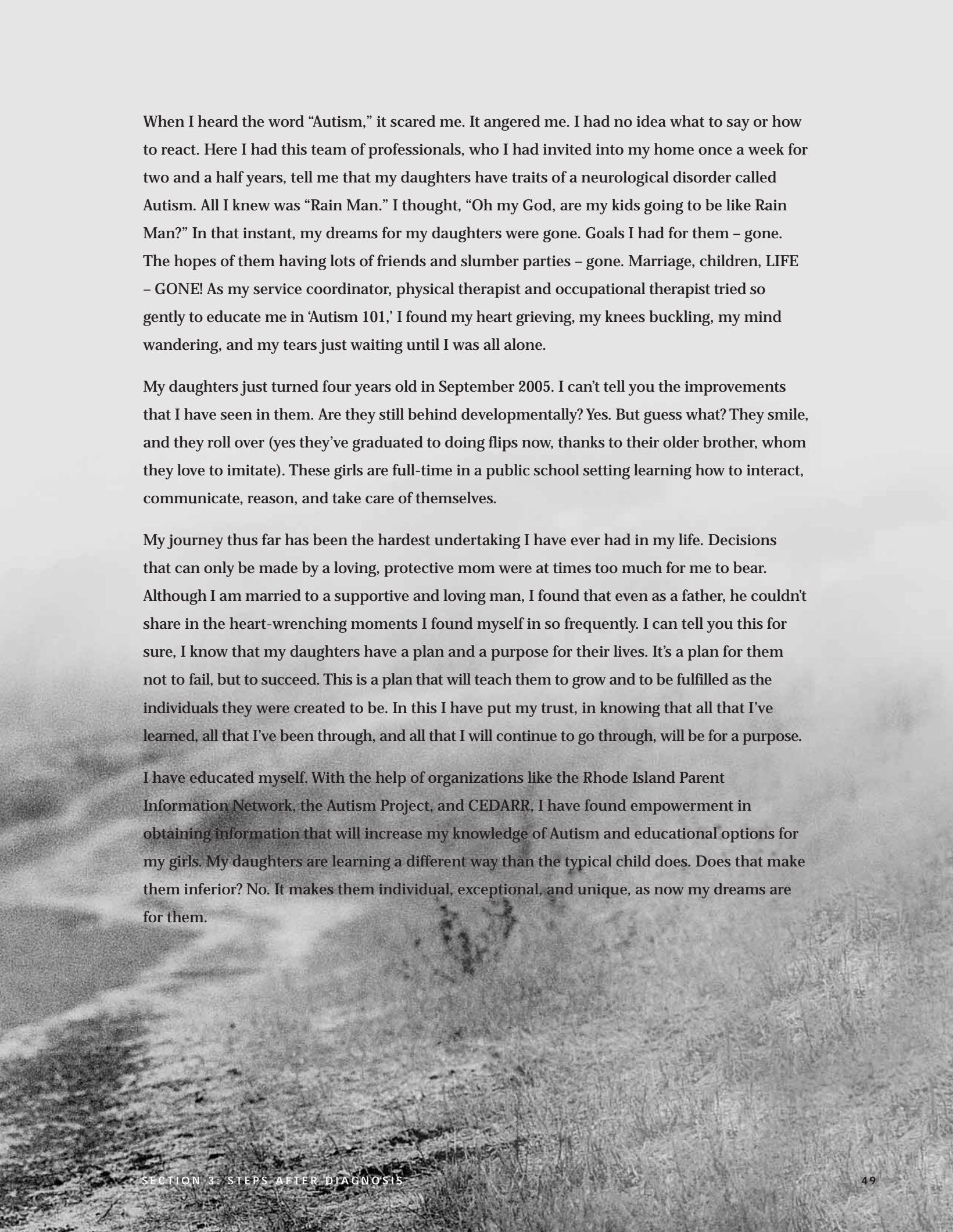


# Individual, Exceptional, and Unique

***Following is Leigh Ann's story, a mother of twin girls with ASD.***

I remember the day distinctly. It was a Tuesday morning, April 2004, when I met with my Early Intervention team. My twin daughters were two years and seven months old. My daughters had done poorly on their tests the week before, and I had to know how delayed they were in their skills. Being that they were preemies, born at 32 weeks, I knew that my daughters would be a little behind on things. They didn't smile when the books said they would; they didn't roll over, stand, sit or even walk when they should have. These girls weren't saying any words, they had no comprehension, and boy, did they move around an awful lot. Twins are known to have some developmental delays, and then they grow out of it. The evaluations had been scored, and in my mind, the evaluations had to be definitely in our favor because, after all, they are preemies and they will catch up.





When I heard the word “Autism,” it scared me. It angered me. I had no idea what to say or how to react. Here I had this team of professionals, who I had invited into my home once a week for two and a half years, tell me that my daughters have traits of a neurological disorder called Autism. All I knew was “Rain Man.” I thought, “Oh my God, are my kids going to be like Rain Man?” In that instant, my dreams for my daughters were gone. Goals I had for them – gone. The hopes of them having lots of friends and slumber parties – gone. Marriage, children, LIFE – GONE! As my service coordinator, physical therapist and occupational therapist tried so gently to educate me in ‘Autism 101,’ I found my heart grieving, my knees buckling, my mind wandering, and my tears just waiting until I was all alone.

My daughters just turned four years old in September 2005. I can’t tell you the improvements that I have seen in them. Are they still behind developmentally? Yes. But guess what? They smile, and they roll over (yes they’ve graduated to doing flips now, thanks to their older brother, whom they love to imitate). These girls are full-time in a public school setting learning how to interact, communicate, reason, and take care of themselves.

My journey thus far has been the hardest undertaking I have ever had in my life. Decisions that can only be made by a loving, protective mom were at times too much for me to bear. Although I am married to a supportive and loving man, I found that even as a father, he couldn’t share in the heart-wrenching moments I found myself in so frequently. I can tell you this for sure, I know that my daughters have a plan and a purpose for their lives. It’s a plan for them not to fail, but to succeed. This is a plan that will teach them to grow and to be fulfilled as the individuals they were created to be. In this I have put my trust, in knowing that all that I’ve learned, all that I’ve been through, and all that I will continue to go through, will be for a purpose.

I have educated myself. With the help of organizations like the Rhode Island Parent Information Network, the Autism Project, and CEDARR, I have found empowerment in obtaining information that will increase my knowledge of Autism and educational options for my girls. My daughters are learning a different way than the typical child does. Does that make them inferior? No. It makes them individual, exceptional, and unique, as now my dreams are for them.

# Treatment and Interventions

“What makes the difference between wishing and realizing our wishes? Lots of things, of course, but the main one, I think, is whether we link our wishes to our work. It may take months or years, but is far more likely to happen when we care so much that we’ll work as hard as we can to make it happen. And when we’re working toward the realization of our wishes, some of our greatest strengths come from the encouragement of people who care about us.” *The World According to Mister Rogers*

## SELECTING A TREATMENT

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There are over 400 different treatments and interventions for Autism Spectrum Disorders (ASDs), which work to different degrees based on the child. It is important to match a treatment or intervention with the needs and strengths of your child. No one treatment works for all children with ASDs. Factors to consider when choosing treatments and interventions include: your child’s age, level of ability (mild, moderate, or severe autism), type of learner (visual/seeing or auditory/hearing), behaviors, and previous treatments. Before deciding on a treatment for your child, learn about the different options and discuss them with your child’s doctor, specialists, and with other families of children with ASDs. Remember that while professionals and others can provide you with advice, you are ultimately the decision maker.

Some suggested questions you can ask to help find the best treatment approach for your child include:

- » Has the treatment been recognized by researchers in the field of ASDs?
- » How has the treatment worked for other children?
- » Will the treatment harm my child?
- » Will the therapy fit into our family routine?
- » What are the qualifications of the therapist?
- » Can the treatment be integrated into other educational programs?
- » What therapies can be used in combination with each other?

- » Is there published scientific support for the treatment (that is, tests or proof of the treatment's effectiveness in medical or educational journals)?
- » What are the financial costs? Is the therapy covered under insurance or Medical Assistance, or is it paid out-of-pocket?

Many treatments have been developed to address a range of social, language, sensory, and behavioral challenges that children with ASDs may show. Different treatments work better for a child at different stages of development. Brief descriptions of some of the better-known treatments are provided below. The treatments and interventions are separated into three categories:

- » Behavioral approaches
- » Biomedical and dietary approaches
- » Medications

Please note that the Rhode Island Department of Health does not endorse or promote any method, treatment, specific medication, or dietary intervention. This information is provided only as part of an overview of the treatment options available. Families should talk to a doctor for advice and more information.

## EVIDENCE-BASED PRACTICES

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Evidence-based practices (EBPs) are focused interventions that:

- » Produce specific behavioral/developmental outcomes for a child,
- » Have been demonstrated as effective in applied research literature, and
- » Can be successfully implemented in educational settings.

To be considered an EBP, National Professional Development Center (NPDC) criteria must be met. This includes:

- » Two randomized or quasi-experimental design studies,
- » Five single subject design studies by three different authors, OR
- » A combination of evidence such as one group and three single subject studies.

*Credit: Odom, Boyd, Hall, & Hume, 2009*

## ANTECEDENT-BASED INTERVENTIONS

This practice is most often used after a functional behavior assessment has been conducted. It is used to address both interfering and on-task behaviors.

#### COMPUTER AIDED/ASSISTED INSTRUCTION

This practice uses computers to teach academic skills and promote communication and language development skills.

#### DIFFERENTIAL REINFORCEMENT

This process is used to increase the frequency of a desirable behavior while eliminating undesirable alternate behaviors.

#### DISCRETE TRIAL TRAINING

Used frequently in Applied Behavior Analysis (ABA) programs, discrete trial training (DDT) include four major components: a brief, distinct instruction or question (the stimulus), a prompt (if needed) to elicit the correct response, a response (correct or incorrect), and an appropriate consequence (reward or ignored/corrected response).

#### EXTINCTION

Extinction refers both to the discontinuation of the reinforcement of a response, and to a decrease in the rate of a conditioned response when it is no longer reinforced.

#### FUNCTIONAL BEHAVIORAL ASSESSMENT

This assessment attempts to determine a behavior's function by looking at what preceded the behavior (its antecedents) and at the outcomes of the behavior (its consequences).

#### FUNCTIONAL COMMUNICATION TRAINING

This practice involves replacing challenging behavior with more desirable behavior that will achieve the same goals for the child. For example, a parent might teach a child who has a meltdown when he becomes overly hungry to use his words to request a snack.

#### NATURALISTIC INTERVENTIONS

This collection of strategies encourages specific target behaviors based on the learner's interests and provides responses that build more elaborate, naturally-reinforcing, appropriate behaviors.

#### PARENT IMPLEMENTED INTERVENTIONS

There is some evidence to suggest that earlier intervention with children with ASDs is better. Training parents as "co-therapists" allows consistent handling and ensures that intervention is appropriate in enhancing children's earliest social relationships.

#### PEER MEDIATED INSTRUCTION/INTERVENTION

This strategy teaches typically-developing children to deliver specific social and communicative behavior to children with social skill deficits.

#### **PICTURE EXCHANGE COMMUNICATION SYSTEM**

Please see the Applied Behavior Analysis section for more information on this strategy.

#### **PIVOTAL RESPONSE TRAINING**

This type of training decreases the frequency of an undesired behavior by reinforcing alternate behaviors.

#### **PROMPTING**

A prompt must be used before (or sometimes while) a child performs a target behavior.

#### **REINFORCEMENT**

This term means strengthening something to make it more durable and long lasting. Teachers and parents can use reinforcements to help children strengthen fragile, newly-learned skills. Over time and with practice, skills become familiar, and children learn to use them consistently and in all kinds of situations.

#### **RESPONSE INTERRUPTION AND REDIRECTION**

This evidence-based practice is used to decrease interfering behaviors, predominately those that are repetitive, stereotypical, and/or self-injurious. It is often implemented after a functional behavior assessment has been conducted.

#### **SELF-MANAGEMENT**

These strategies focus on techniques that improve social behavior by keeping a daily count of the number of times a child engages in the desired behavior. The child is given a reward if the given number is achieved in a certain amount of time.

#### **SOCIAL NARRATIVES**

Through short sentences or phrases, social narratives can teach new social skills and encourage individuals to regulate their behavior during social interactions.

#### **SOCIAL SKILLS GROUPS**

These small groups use instruction, role-playing, and feedback to teach people with ASDs how to interact appropriately with their typically-developing peers.

#### **SPEECH GENERATING DEVICES**

These portable electronic devices can produce synthetic or digital speech for the user. They target skills that help children with ASDs communicate effectively with others in a variety of situations and can be used by those who have limited or no verbal speech from early childhood through high school.

#### STRUCTURED WORK SYSTEMS

Structured work systems are an element of structured teaching, which is an instructional strategy that emphasizes visual supports. The individual work system is defined as a visually organized space where learners independently practice skills that have been previously mastered under the direct supervision of an adult.

#### TASK ANALYSIS

During task analysis, a task is analyzed into its component parts so that those parts can be taught through the use of chaining and total task presentation. Chaining is the linking of component behaviors into a more complex, composite behavior. Tasks can be taught in order (forward chaining) or backwards, with the last step mastered first (backward chaining).

#### TIME DELAY

This strategy aims to fade instructional prompts by inserting a delay between giving an instruction and stepping in to prompt a response. The time delay can be progressive (gradually increased) or constant.

#### VIDEO MODELING

This process videotapes behaviors related to autism to develop the child's ability to memorize, imitate, and adapt those behaviors.

#### VISUAL SUPPORTS

By making auditory information visual, visual supports can organize a sequence of events, supplement verbal instruction, and cue communication. They can take various forms, including written words, pictures, gestures, objects in the environment (e.g., supplies for an activity sitting on a table where the activity will occur) and arrangements of the environment (e.g., chairs set up in a reading circle).



**PRACTICES BY AGE AND DOMAIN**

EVIDENCE-BASED PRACTICES	Academics & Cognition			Behavior			Communication			Play			Social			Transition			
	EC	EL	MH	EC	EL	MH	EC	EL	MH	EC	EL	MH	EC	EL	MH	EC	EL	MH	
1. Antecedent-based Interventions	√	√	√	√	√	√													
2. Computer Assisted Instruction	√	√	√																
3. Differential Reinforcement				√	√	√	√	√	√				√	√	√				
4. Discrete Trial Training	√	√		√	√		√	√		√	√		√	√					
5. Extinction				√	√	√													
6. Functional Behavioral Assessment				√	√	√	√	√	√										
7. Functional Communication Training				√	√		√	√											
8. Naturalistic Interventions							√	√	√				√	√	√				
9. Parent Implemented Interventions				√	√		√	√		√	√		√	√					
10. Peer Mediated Instruction/Intervention							√	√	√				√	√	√				
11. Picture Exchange Com. System				√	√	√	√	√	√				√	√	√				
12. Pivotal Response Training	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√				
13. Prompting	√	√	√	√	√	√	√	√	√										
14. Reinforcement	√	√	√	√	√	√	√	√	√										
15. Response Interruption & Redirection	√	√	√	√	√	√													
16. Self-Management	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
17. Social Narratives	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√				
18. Social Skills Groups							√	√	√				√	√	√				
19. Speech Generating Devices (VOCA)							√	√	√										
20. Structured Work Systems	√	√	√							√	√	√				√	√	√	
21. Task Analysis	√	√	√	√	√	√	√	√	√				√	√	√				
22. Time Delay		√						√			√			√					
23. Video Modeling	√	√	√				√	√	√	√	√	√	√	√	√				
24. Visual Supports	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√

**KEY**

EC = EARLY CHILDHOOD    EL = ELEMENTARY    MH = MIDDLE / HIGH SCHOOL

# Sample Sensory Diet

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## PURPOSE:

- » To stimulate the child's senses throughout the day in order to keep him or her focused.
  - » To use sensory activities to help a child stay calm and focused.
- 

## MOVEMENT (VESTIBULAR SYSTEM) AND MUSCLE (PROPRIOCEPTIVE SYSTEM)

**Procedure:** Use movement of the muscles, joints, and eyes to remain focused and attentive to task.

### **Movement that Creates a Calming Effect**

- » Swinging – rhythmically – calming
- » Slow rocking over ball or bolster

### **Movement that Creates an Alerting Effect**

- » Jumping on trampoline
- » Scooter board – pulled by adult (child pulls on hoola hoop to speed up)
- » Scooter board – push or pull self using hands (lying prone) or feet (sitting)
- » Hanging from bar
- » Climbing ladder
- » Swinging with irregular movement – stops/starts, bumps

### **Movement that Creates Organizing and Calming Effects**

- » Weighted vest worn while walking, moving
- » Wrist or ankle weights worn while walking, moving

### **Deep Pressure that Creates Organizing and Calming Effects**

- » Rolling a therapy ball or paint roller with pressure on the back and limbs
- » Theraputty
- » Wearing a weighted shoulder pad, weighted lap pad, or blanket
- » Wearing a pressure vest
- » Vibration
- » Foot squeeze, upper chest squeeze, shoulder pushes
- » Arm/hand massage, finger pulls

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ORAL SENSORY SYSTEM (AUDITORY/HEARING, OLFACTORY/SMELLING,  
GUSTATORY/TASTING SYSTEMS)

**Procedure:** Use muscle, oral, and smell stimulation to remain focused and attentive to task.

**Activities that Create a Calming/Organizing Effect**

- » Eating crunchy foods
- » Eating chewy foods
- » Sucking thick liquids (e.g., milkshakes)

**Activities that Create an Alert Effect**

- » Eating sour foods
- » Eating spicy foods

**Activities that Create a Calming Effect**

- » Relaxation
- » Playing music nearby  
or with a headset
- » Wearing headset with no music –  
to block noise (for defensiveness)



## BEHAVIORAL APPROACHES

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### APPLIED BEHAVIORAL ANALYSIS

Applied Behavior Analysis (ABA) is one of the only interventions that has proven results for people with ASDs. It is based on the theory that all learned behaviors have an antecedent (what happened before the behavior) and a consequence (what happened after the behavior). This means that people are motivated by positive or negative consequences to repeat or not to repeat a behavior. In this treatment, a skill is broken down into small steps and taught in a one-on-one teaching session. The child is given repeated learning opportunities with clear, simple cues and immediate and consistent rewards for correct responses. Skills are also practiced outside of the classroom in environments such as the home and community settings (e.g., park, store, restaurant). Negative behaviors (e.g., tantrums and aggression) are not rewarded. Instead, more appropriate behaviors are taught in their place. Families can research ABA programs to ensure that providers are certified by accessing the following websites: [www.bacb.com](http://www.bacb.com) (Behavior Analysis Certification Board) or [www.featri.org](http://www.featri.org) (Families for Effective Autism Treatment–FEAT).

### AUDITORY INTEGRATION THERAPY

This method of treatment is based on the theory that some children are very sensitive to certain sounds, making them painful to hear. Auditory integration therapy reduces over-sensitivity to sound. It may involve having the child wear headphones to listen to a variety of sound frequencies and music. This treatment is done over a period of time. The effectiveness of this method has not been proven. For more information, visit the website [www.sait.org](http://www.sait.org)



#### FLOOR TIME

Floor Time (or Greenspan Floor Time) encourages the child to interact through play. The four goals of Floor Time include encouraging attention and affection, fostering communication, encouraging the use of ideas and feelings, and promoting logical thinking. This method focuses on the emotional growth of the child and can be used in conjunction with other therapies and treatments. For more information, visit the website [www.stanleygreenspan.com](http://www.stanleygreenspan.com)

#### OCCUPATIONAL THERAPY

Occupational therapy may help children with ASDs to develop appropriate social, play, and learning skills. It can also address sensory integration issues. The occupational therapist helps the child in performing daily tasks such as getting dressed, appropriately responding to information coming through the senses, and interacting and communicating with others. As children grow, occupational therapy gives them the skills needed to lead independent and satisfying lives. For more information, visit the website [www.wfot.org](http://www.wfot.org)

#### PHYSICAL THERAPY

Pediatric physical therapists diagnose and treat infants, children, and adolescents with a variety of disorders. Treatments focus on improving gross and fine motor skills, balance and coordination, strength and endurance, and cognitive and sensory processing/integration. Physical therapists work on building the child's strength and endurance through physical and strength-building exercises. For more information, visit the website [www.fsbpt.org](http://www.fsbpt.org)

#### PICTURE EXCHANGE COMMUNICATION SYSTEM

The Picture Exchange Communication System (PECS) allows a child to communicate using pictures or a series of pictures to form a sentence. The goals of picture exchange are for a non-speaking child to develop communication skills and to interact with others. PECS requires the child to hand the parent/caregiver or therapist a picture (icon or symbol) of something he or she wants. Basic concepts such as numbers, colors, shapes, and reading can be taught by using this method. PECS does not require expensive materials and it can be easily incorporated into any existing program. For more information, visit the website [www.pecs.com](http://www.pecs.com)

#### PICTURE REHEARSAL

Picture rehearsal is a method that uses sequenced pictures and a script that depict when, where and how to use a specific sequence of behaviors. The scenes are written using a positive reinforcement framework and have three components: the antecedents (A), the behavior to increase (B), and the consequence (C). The goal of Picture Rehearsal is to teach the child ways to control his or her responses to stressful situations. It combines a proven behavioral approach to learning (A-B-C) with the visual supports that are both necessary and effective in assisting a child with an ASD to learn. For more information, visit the website [www.grodencenter.org](http://www.grodencenter.org)

#### RELAXATION THERAPY

Relaxation therapy involves learning how to change a tense body state to a relaxed one, thereby reducing stress. The child learns to tell the difference between muscles that are tense and muscles that are relaxed. This is taught in a structured way, beginning with readiness skills, moving to sequentially tightening and relaxing larger muscle groups, and adding breathing exercises. The child responds to relaxation prompts through daily practice and is taught when to use this skill. The method aims to help the child identify both bodily signs of stress and situations that may cause those signs. For more information, visit the website [www.grodencenter.org](http://www.grodencenter.org)

#### SENSORY INTEGRATION

Children with ASDs are often over- or under-sensitive or may lack the ability to integrate their senses. Sensory integration therapy, usually done by an occupational therapist, focuses on desensitizing or retraining the senses (smell, taste, sight, touch, or hearing). For example, if a child has difficulties with the sense of touch, therapy might include handling a variety of materials with different textures. Opportunities for sensory integration therapy can be worked into the child's daily routine in the home, school, or other community settings. Many children with ASDs need to incorporate sensory activities throughout their day. These activities are developed by the therapist and tailored to each child's needs in a plan called a Sensory Diet. A sample Sensory Diet is provided on the next page. For more information, visit the website [www.sensoryint.com](http://www.sensoryint.com)

#### SOCIAL COMMUNICATION, EMOTIONAL REGULATION, AND TRANSACTIONAL SUPPORTS MODEL

The Social Communication, Emotional Regulation, and Transactional Supports (SCERTS™) Model is a comprehensive, multidisciplinary approach to improving communication and social/emotional abilities by addressing the core challenges faced by children with ASDs and related social-communicative disabilities and their families. It is based on the belief that children do best when there is an educational focus on communicating with others and developing relationships (Social Communication), enhancing the ability to stay in a well-regulated state for learning and interacting (Emotional Regulation), and supporting children and families in various ways (Transactional Support). The SCERTS™ model focuses on functional skills in everyday activities across settings and is based on the unique learning style of children with ASDs. It is not an exclusive approach; it provides a framework in which practices from other approaches may be integrated. Assessment occurs through observation of children in different settings and with different partners using a detailed curriculum-based assessment and parent report. It can be used with a wide range of developmental abilities, including both preverbal and verbal children. It is also relevant for older school-age children and adults. Particular emphasis is given to parent-professional collaboration. For more information, visit the website [www.scerts.com](http://www.scerts.com)

#### SOCIAL STORIES

Social stories were developed as a tool for teaching social skills to children with ASDs. Through a story developed about a particular situation or event, the child is given information to help him or her understand the expected or appropriate response. The stories can be written by anyone, are specific to the child's needs, and are written in the first person, present tense. They frequently use pictures, photographs, or music based on the child's abilities and interests. Before developing and using a social story, it is important to identify how the child interacts socially and to determine which situations are difficult and what makes them difficult. Situations that are frightening, produce tantrums or crying, or make a child withdraw or want to escape are examples of where a social story could help. Only one problem should be addressed in a social story at a time. The most important element of a social story is to keep it positive 100% of the time. For more information, visit the website [www.thegraycenter.org](http://www.thegraycenter.org)

#### SPEECH & LANGUAGE THERAPY

Speech and language therapy begins with a complete evaluation of the child's ability to communicate. No single treatment has been found to improve communication in all individuals who have ASDs. Once a diagnosis is made, speech therapy should begin as soon as possible. Speech therapy should be tailored to the child, target both behavior and communication, and involve families or primary caregivers. The goal of therapy should be to improve useful, functional, and social communication. There are many treatments available based upon a child's strengths and needs. Treatment should include periodic evaluations by a speech-language pathologist. Occupational and physical therapists may also get the child ready to learn when working on language development. For more information, visit the website [www.asha.org](http://www.asha.org)

#### TREATMENT AND EDUCATION OF AUTISTIC AND COMMUNICATION RELATED HANDICAPPED CHILDREN

**Treatment and Education Autism and Communication Related Handicapped Children (TEACCH)** is an internationally recognized, structured teaching approach based on the idea that the environment should be adapted to the child with an ASD, not the child to the environment. Organizing the physical environment, developing schedules and work systems, making expectations clear, and using visual materials have been effective ways of developing skills and allowing children with ASDs to use these skills independently. Rather than teaching a specific skill or behavior, the TEACCH approach aims to provide the child with the skills to understand his or her world and other people's behaviors. Communication skills, social skills, inclusion, and curriculum are all designed to meet the child at his or her current level of functioning and to take that child as far as he or she can go. For more information, visit the website [www.teacch.com](http://www.teacch.com)

#### ADDITIONAL THERAPIES

- » Art therapy gives tactile (feeling, touch), visual, and auditory (hearing) stimulation. It can provide a nonverbal way for a child with an ASD to communicate and express himself or herself.
- » Music therapy is used for speech development and language comprehension. Songs teach language and help children put words together.
- » In Hippotherapy, children use horseback riding to increase muscle tone and sensorimotor response (integration of sensory and motor aspects of bodily activity).



## BIOMEDICAL AND DIETARY APPROACHES

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### ANTI-YEAST (OR ANTIFUNGAL) DIET

A diet sometimes used in the treatment of children with ASDs is the Anti-Yeast Diet. Advocates of this diet say that children with ASDs may have “leaky guts”—tiny holes in their intestinal tracts that may be caused by an overgrowth of yeast, which may contribute to their behavioral and/or medical problems. The Anti-Yeast Diet removes yeast from the diet and/or uses nutritional supplements and anti-fungal drugs. It is important to talk to a doctor before trying this diet. For more information about the Anti-Yeast Diet, visit the Autism Network for Dietary Intervention website at [www.autismndi.com](http://www.autismndi.com)

### GLUTEN FREE/CASEIN FREE DIET

Some children with ASDs may have allergies to certain foods or chemicals. Advocates of the Gluten Free/Casein Free (GFCF) Diet say that these food intolerances or allergies may contribute to behavioral issues that are associated with ASDs. The theory is that the child’s digestive system cannot break down peptides from foods that contain gluten and casein, impacting the child’s brain function and ability to process information. Casein is found in dairy products and gluten is found in wheat, oats, and rye. The GFCF Diet removes all products that contain gluten and casein from the diet to monitor any resulting positive changes in behavior. It is important to talk to a doctor before trying this diet. For more information, visit the Autism Network for Dietary Intervention website at [www.autismndi.com](http://www.autismndi.com)

### SECRETIN (HORMONES)

Secretin is a hormone that is produced by the small intestine to help the body with the digestion process. Some people believe that giving children secretin improves some symptoms of ASDs, such as sleep patterns, eye contact, language skills, and alertness. It is important to note that the Food and Drug Administration (FDA) only approves secretin in a single dose, and there are no studies that show it is safe to use. Additional information can be accessed through the Autism Research Institute website at [www.autismresearchinstitute.com](http://www.autismresearchinstitute.com)

### VITAMINS, MINERALS, AND SUPPLEMENTS

Children with intestinal disorders and chronic intestinal inflammation may not absorb nutrients needed to maintain the immune system. Some children with ASDs may have low or high levels of vitamins and minerals. When considering the addition of vitamins and minerals to a child’s diet, the family should talk to a doctor who is knowledgeable in nutritional therapy. A doctor can evaluate the child’s nutritional status through a blood test or clinical assessment.

## MEDICATIONS (PSYCHOPHARMACOLOGIC TREATMENTS)

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There are many medications that were developed for other conditions but have been found effective in treating some of the symptoms and behaviors associated with ASDs. The goal of medications is to reduce these behaviors to allow the child with an ASD to take advantage of educational and behavioral treatments.

Families should be clear about what they want to see improved through medication. Symptoms such as disrupted sleep or appetite, increased anxiety, or increased aggressive behavior may be addressed through the use of medication. Although medication will not change a child's IQ or cure an ASD, it may improve some symptoms and allow a child to do better in school, to tolerate change, or to get along better with family members and peers. Some children, for reasons that are not well understood, simply do not do very well on medication.

### QUESTIONS FOR THE DOCTOR

The following are some suggested questions that families should ask their doctors before beginning medications:

- » How safe is the drug?
- » What are the side effects of the drug?
- » Is there any research on the drug and its use in children with ASDs?
- » How is it given (pills or liquid)?
- » Are there possible interactions with other drugs, vitamins, or foods?
- » How will my child be monitored and by whom?



When medications are begun, there are some basic rules that should be followed:

- » Given the complexity of medications, drug interactions, and the unpredictability of how each patient may react to a particular drug, families should seek out and work with a medical doctor with an expertise in the area of medication management.
- » Evaluations should include a thorough medical history.
- » Risks and benefits should be discussed.
- » Appropriate medications with the fewest side effects should be started first.
- » The lowest possible dose should be used at first to avoid adverse reactions.
- » Medications should be used long enough and in doses that will show if they work.
- » Objective data, such as rating scales or measuring discrete behaviors, should be used to assess efficacy. This is particularly important when many people weigh in on a medication trial.
- » The family should always be allowed to end a medication trial, unless doing so would harm the child. Families should be given clear instructions on how to stop a medication.
- » Medications should never be used for the convenience of families, teachers, or staff working with a child or adult with an ASD.
- » Regular monitoring is always necessary. If medications are not effective, they should be changed or stopped.
- » At no time should the child be overly sedated, cognitively impaired, or unable to function.
- » Lastly, although medication might not have been effective in the past, it may be worth trying again in the future. Weight gain, growth, and greater maturity may, at times, allow a medication that didn't work in the past to be more therapeutic.

Families can get more information about medications through the National Institute of Health website at [www.nih.gov](http://www.nih.gov)

# Matthew's Story

***Following is Deb's story about her son Matthew, who has an ASD, and his struggles with education.***

In March 1985, a beautiful, bouncing baby boy was born. In January 1987, he was diagnosed with autism, and his family's life changed forever. Matthew looked like the three B's of babies with autism: big, blonde, and blue-eyed. At least that's what many looked like in 1987. Back then, autism showed up in 1 out of 10,000 births, with 3 out of 4 being males. We were a bit of an oddity then, but things have certainly changed since.

It was a good three days before the diagnosis set in and the grief began. It was deep and nauseating, but eventually floated away like fog after a good rain. After all, he was still my Matthew. Could life really change that much? We found out soon just how much. When our school system wanted to label him with mental retardation after spending 15 minutes "observing" him, I knew that it would be up to my husband and I to advocate for the best care possible; nobody would be doing this for us.

We ended up in a pre-hearing conference with our school system and won the right to have him educated at the Groden Center in an integrated pre-school program. Back then, very few programs provided integration with typically developing children, but the few studies I had read and our gut told us that this would be extremely important for Matt's success. Placing him there when he was three was the first good decision we made, and sending him back to his home school in Coventry three years later was the second.

When he finally said "mom," he was five years old, and shortly after, he became toilet-trained, which were miracles in themselves. He left the Groden program toilet-trained, using some basic words, and able to read close to 200 sight words. I still keep the flash cards in my bed stand to remind me of where we've been. He entered Kindergarten with a trained one-on-one teaching assistant at Washington Oak School in Coventry. Little did I know that the wonderful peers he came to know as friends on that first day in September of 1991 would become the young adults with whom he would graduate from Coventry High School in June 2004.

I would love to say that the wonderful assistants and great peers he had over the years were enough to make everything perfect in school. But that would not be true. His autism, combined with a diagnosis of Bipolar Disorder at the age of nine, made his life and ours quite

challenging. Now we had a child with mood swings who could not tell us how he felt. The crying, the anger, the anxiety were all part of the everyday experience throughout his school years. The challenges to our school system as well as to our family, especially to his brother and sister, were on going. Just when we thought we had the right direction and supports, things would change again. There were days when his OCD was so bad that it would take him two hours just to get from his bedroom to the morning school bus. Many of those days, we just pulled down the shades and stayed home.

But the reality is that Matthew's autism has brought us joys greater than any sorrow we experienced. The friends, doctors and support we have been blessed with along the way are simply the best of the best. There have been "moments of greatness" I didn't believe we would ever have experienced: the duet he and I sang in a school cabaret with a standing ovation of 400 people, the wilderness field trip where he had to climb over a ten-foot wall with six friends under him helping him over the top, the many years he sang the Star Spangled Banner for an auditorium full of people, or when he read Green Eggs and Ham to Kindergarten kids when he was in 5th grade, are just a handful of examples. And most importantly, walking across the stage and receiving his high school diploma with 450 of his classmates was a moment that will be etched in our hearts forever.

At 20 years old, we are getting ready for his adult life to begin. I'm sure there will be more challenges ahead. But I've learned that life has challenges for all of us. Because of his autism, Matthew has brought to our lives a sense of compassion, sensitivity and empathy we may never have known. The world could use a few more compassionate people ... maybe that's what autism is really meant to do!

# Special Education

The public schools are responsible for providing all children with a Free Appropriate Public Education (FAPE).

If a child has an Autism Spectrum Disorder (ASD) that is affecting his or her progress in the general curriculum (i.e., the same curriculum for non-disabled children) or if the disability affects participation in appropriate activities, a referral for special education and related services can be made.

Once a referral is made to the public school system, the school system has ten school days upon the receipt of the referral to conduct a meeting to review the referral. The purpose of the meeting is to review the referral information and to determine if additional data is needed for a review, including any evaluations necessary to determine eligibility. The participants of this meeting should include a group of qualified professionals and the parent/caregiver. If, at this meeting, the team determines that an initial evaluation is not needed, the parent/caregiver must be notified within ten school days.

If, at this meeting, the team determines that further information and evaluations are needed, the team would then decide which evaluations are necessary. The family must sign a “consent to evaluate” form, which gives the school department permission to evaluate their child. The public school system has ten days upon receipt of permission to begin the evaluation process.



## SPECIAL EDUCATION EVALUATIONS

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Evaluations are required to determine if a child is eligible for special education and related services, as well as for determining ongoing eligibility. The following is a list of evaluations that the school district may conduct after the parent/caregiver gives their consent for those evaluations that have been identified as necessary to determine if their child has a disability or for ongoing eligibility determination.

- » Social History (School Social Worker)
- » Medical Evaluation (Child's Doctor)
- » Psychological Evaluation (School Psychologist)
- » Language and Communication Evaluation (Speech and Language Therapist)
- » Educational Evaluation (Diagnostic Prescription Teacher [DPT] or Special Education Teacher)
- » Sensory or Fine Motor Evaluation (Occupational Therapist)
- » Physical Development or Gross Motor Evaluation (Physical Therapist)
- » Adapted Physical Educational (APE) Evaluation (School's APE Teacher or Physical Education Teacher)
- » Functional Behavioral Assessment (FBA) (School Psychologist, Teacher, or Team of Identified Individuals)

The school department must begin the initial evaluations no later than 10 school days after the receipt of parental consent and has 60 calendar days after receipt of parental consent to complete the initial evaluations.

Upon completion of the evaluations, the evaluation team will reconvene with the family to discuss the child's evaluation results and to determine if the child is a child with a disability and in need of special education and related services. Once a child with an ASD has been determined eligible for special education, he or she should be found eligible under the primary disability category of Autism. Autism includes:

- » Autism
- » Asperger Disorder
- » Childhood Disintegrative Disorder
- » Pervasive Developmental Disorder—Not Otherwise Specified (PDD-NOS)
- » Rett's Disorder

## INDIVIDUALIZED EDUCATION PROGRAM

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The Individualized Education Program (IEP) is the document that serves as a written agreement between the student's parent/caregiver and the school system. An IEP team meeting is held to develop an IEP for the child after initial eligibility and then at least annually as long as the child qualifies for special education and related services. Families and educators have the right to convene an IEP meeting prior to the date of the yearly meeting.

### IEP TEAM

Minimally, the IEP team must comprise the parents/caregivers of the child, not less than one regular education teacher, not less than one special education teacher or not less than one special education provider, a representative of the Local Education Agency (LEA), an individual who can interpret the instructional implications of the evaluation results, other individuals invited at the discretion of the parent or LEA, and the child, if appropriate [refer to §300.321 Rhode Island Board of Regents for Elementary and Secondary Education Regulations Governing the Education of Children with Disabilities]. Other individuals include the child's occupational therapist, speech and language therapist, physical therapist, social worker, or home-based therapy agency representative. A packet containing information about families' rights under the law, called "Procedural Safeguards," should be handed to or offered to families at every meeting. For more information about Rhode Island's Procedural Safeguards, see [www.ride.ri.gov/Special\\_Populations/Dispute\\_resolution](http://www.ride.ri.gov/Special_Populations/Dispute_resolution)

### IEP MEETING

The opening of the meeting should include introductions of all participants. It is important that family has a clear understanding of who is at the meeting and what their roles are in the development of the child's program.

At the IEP meeting, the student's current abilities and strengths are discussed, along with his or her functional performance and academic achievement. Measurable annual academic or functional goals and short-term objectives are developed. Through this process, the special education and related services needed by the child are identified. The team decides where the services will be provided. Options include the regular education or other locations. Regular education locations refer to classroom, school, or community settings that a student would attend if not disabled. Other settings include special classes, schools, homes, hospitals, or residential settings. The Individuals with Disabilities Education Act (IDEA) presumes that the first placement option considered for each student with a disability is the school that the child would attend if he or she were not disabled, with appropriate aids and services to facilitate such placement. If a determination is made that the student cannot be educated satisfactorily



in the regular education environment, even with additional aids and services the student may then be placed in a setting other than the regular education classroom (see the Other Educational Settings section on page 72).

Placement decisions must be determined on the basis of each student's abilities and needs, and not solely on factors such as the category of disability, significance of disability, availability of special education and related services, availability of the space, and administrative convenience.

For more information about the IEP process, visit the Rhode Island Technical Assistance Project website at [www.ritap.org/iep](http://www.ritap.org/iep)

For more information on resources and professional development opportunities, access the Rhode Island Technical Assistance Project/Autism Support Center at Rhode Island College at [www.ritap.org/asd](http://www.ritap.org/asd)

#### IEP MEETING TIPS

The following is a list of tips created by families to help make sure that your IEP meeting is a positive experience.

- » Bring a friend or family member to the meeting with you.
- » Go to the meeting prepared. Bring information about your child's strengths and needs using examples from what you see at home or in other settings.
- » Carry written information in a folder or notebook.
- » Shake hands and acknowledge other people at the meeting. Sit with the team.
- » Remember, you are part of the decision-making process.
- » Ask questions and ask for clarification of anything that you do not understand.
- » Focus on the issues at hand. Do not be sidetracked by other issues, such as past experiences.
- » Remain as friendly as possible. Keep your emotions in control.
- » Make your proposal and expect to get what your child needs. Be flexible enough to accept minor revisions, but be firm on major issues.
- » Feel confident to end the meeting if it seems that no more progress can be made. Request a new appointment for a fresh start.
- » Remember, you are advocating for the safety, health, well being, and future of your child. If you do not do it, who will?

Section 504 covers qualified students with disabilities who attend schools receiving federal financial assistance. To be protected under Section 504, a student must be determined to: (1) have a physical or mental impairment that substantially limits one or more major life activities; (2) have a record of such an impairment; or (3) be regarded as having such an impairment. Section 504 requires that school districts provide a free appropriate public education (FAPE) to qualified students in their jurisdictions who have physical or mental impairments that substantially limit one or more major life activities.

Section 504 requires recipients to provide to students with disabilities appropriate educational services designed to meet their individual needs to the same extent as the needs of students without disabilities. An appropriate education for a student with a disability under the Section 504 regulations could consist of education in regular classrooms, education in regular classes with supplementary services, and/or special education and related services. There are no impairments which automatically mean that a student has a disability under Section 504.

An impairment in and of itself is not a disability. The impairment must substantially limit one or more major life activities in order to be considered a disability under Section 504. A medical diagnosis alone does not suffice as an evaluation for the purpose of providing FAPE. A physician's medical diagnosis may be considered among other sources in evaluating a student who has or is believed to have an impairment that substantially limits a major life activity. Other sources to be considered include aptitude and achievement tests, teacher recommendations, physical condition, social and cultural background, and adaptive behavior. Section 504 regulations require school districts to draw upon a variety of sources in interpreting evaluation data and making placement decisions.

The Office for Civil Rights (OCR) in the US Department of Education provides technical assistance to school districts, families, and students upon request. Additionally, regulations and publicly issued policy guidance is available on the OCR's website at [www.ed.gov/policy/rights/guid/ocr/disability.html](http://www.ed.gov/policy/rights/guid/ocr/disability.html). 504 Frequently Asked Questions can be found at <http://ed.gov/about/offices/list/ocr/504faq.html#interrelationship>

## OTHER EDUCATIONAL SETTINGS

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If the IEP team makes a determination that the student cannot be satisfactorily educated in the regular education environment, the student may be placed in another setting. This can include an out-of-district placement. The IEP that is developed for an out-of-district placement must be developed with participation from a representative of the private school

or facility. The time frame and decision regarding this placement is made and reviewed at least annually by the IEP team.

For a list of schools for children with disabilities in Rhode Island, see the Community Resources and Websites section or visit [www.ride.ri.gov/RIDE/SchoolDirectory/Default.aspx](http://www.ride.ri.gov/RIDE/SchoolDirectory/Default.aspx)

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## INCLUSION INSTITUTES

Offered by Sherlock Center on Disabilities at Rhode Island College, Inclusion Institutes provide the opportunity for school personnel and parents to work in teams in planning for the inclusion of individual children who have developmental disabilities. Teams usually consist of the child's parents, a special educator, teaching assistants, therapists, and others. Most teams also include either a principal or a special education director. Each Institute consists of one full day. Register online at [www.ric.edu/sherlockcenter/training.html](http://www.ric.edu/sherlockcenter/training.html)

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## TAILORING SPECIAL EDUCATION FOR STUDENTS WITH ASDs

Based on 2001 recommendations by the National Research Council on Educating Children with Autism, the educational goals for students with ASDs are the same as those for other children (e.g., independence and social responsibility). These goals imply progress in social and cognitive abilities, verbal and nonverbal communication skills, and ability to adapt in different situations (e.g., can perform skills at home or school); reduction in behavioral difficulties; and generalization of abilities across environments.

Students with ASDs benefit from programming geared to the core deficits of the disorder. Joint attention (showing or pointing to direct attention) and symbol use (understanding the meaning of words and gestures, using objects functionally and in symbolic play) are two of the core ASD communication deficits that must be addressed.

In 2001, the National Research Council published its recommendations regarding interventions for children with ASDs up to eight years of age. Some common characteristics of appropriate education programs are:

- » **Intervene as early as possible.** There are windows of opportunity for involvement that are lost without early intervention.
- » **Intensity matters.** Early intervention, preschool, and education services should be engaging, intense, and consistently provided. This level of engagement is needed to counter withdrawal and to further a child's progress at key stages of early brain development.

SIX INTERVENTIONS THAT SHOULD BE PRIORITIZED FOR CHILDREN WITH ASDs INCLUDE:

- 1) Teaching of functional and spontaneous communication.
- 2) Social instruction in various settings.
- 3) Play skills with peers and toys.
- 4) Instruction leading to generalization of cognitive goals.
- 5) Positive approaches to problem behaviors.
- 6) Functional academic skills.

- » **Plan developmentally-appropriate educational activities.** The child should be engaged in one-to-one or small group settings to achieve specific objectives.
- » **Priority interventions.** The priority interventions are teaching of functional and 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.
- » **Opportunities for interaction with typically-developing children.** Instructional settings should maximize opportunities to interact with typically-developing children.
- » **Professionals with specialized training.** Professionals require ongoing, specialized training due to the unique features of ASDs.
- » **Family information and education.** Families need information and education to participate in their children's education and to assist in generalizing skills and behaviors.

## EDUCATIONAL/SECONDARY TRANSITION

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Educational Transition is the process of preparing students for life after high school and includes planning for post-secondary education or training, employment, or community living. In Rhode Island, the Department of Elementary and Secondary Education, Office of Special Populations and the Transition Council oversee the secondary transition process and actively work with students, parents, local school districts, and other state and local agencies to promote an effective, statewide system of secondary transition services for students with disabilities.

### REGIONAL TRANSITION CENTERS

These centers provide direct technical support, training, and information on transition services to school personnel in each region and assist in the development of statewide training and information activities (See the Community Resources and Websites section for a list of Regional Transition Centers).

#### REGIONAL VOCATIONAL ASSESSMENT CENTERS

These centers provide vocational assessment services for students aged 14 to 21 years who are eligible for the services of the Department of Human Services/Office of Rehabilitation Services. They assist students with their personal career goals through career counseling, vocational testing, and community work experience. (See the Community Resources and Websites section for a list of Regional Vocational Assessment Centers.)

#### TRANSITION ACADEMIES

These educational programs offer students with disabilities, 18 to 21 years old, the opportunity to complete their high school education on a college campus and/or in various employment and community settings. They are geared towards students who have completed or nearly completed the academic courses necessary for graduation and would benefit from an additional one to two years to acquire the functional life skills, vocational skills, and social skills necessary to be better prepared for adult life. Potential candidates must be in special education with an Individualized Education Program (IEP), be currently enrolled in school, and near completion of their academic program. Candidates must also be eligible for services through the Office of Rehabilitation Services and must have a current application with that office. Application must be recommended by the student's IEP team and include an Office of Rehabilitation Services Counselor's recommendation. Applications are available through the student's high school or Special Education Administrator.

#### RESOURCES AND SUPPORT MATERIALS FOR FAMILIES AND YOUTH

##### *College Resources & Planning: A RI Guide for Youth in Transition*

This directory helps students who receive supports through IEPs or 504 Plans to learn about post-secondary education opportunities. The document can be found at [www.ric.edu/sherlockcenter/publications/CollegeGuide.pdf](http://www.ric.edu/sherlockcenter/publications/CollegeGuide.pdf)

##### *Employment Resources & Planning: A RI Guide for Youth in Transition*

Designed for students in transition, this guide walks students through the steps of planning an employment search. The workbook format encourages students to enter their own information and complements School to Career training programs and curricula. The document can be found at [www.ric.edu/sherlockcenter/publications/ERPlan.pdf](http://www.ric.edu/sherlockcenter/publications/ERPlan.pdf)

##### *Transition Resource Directory*

This directory of transition resources and services helps teachers, parents, and students identify resources for their transition from school to adult life. The document can be found at [www.ric.edu/sherlockcenter/publications/RITransRes.pdf](http://www.ric.edu/sherlockcenter/publications/RITransRes.pdf)

# The School Years

***The following story is written by Nancy, the mother of Cory, who has an ASD. Nancy's story picks up with her son's journey through the school ages.***

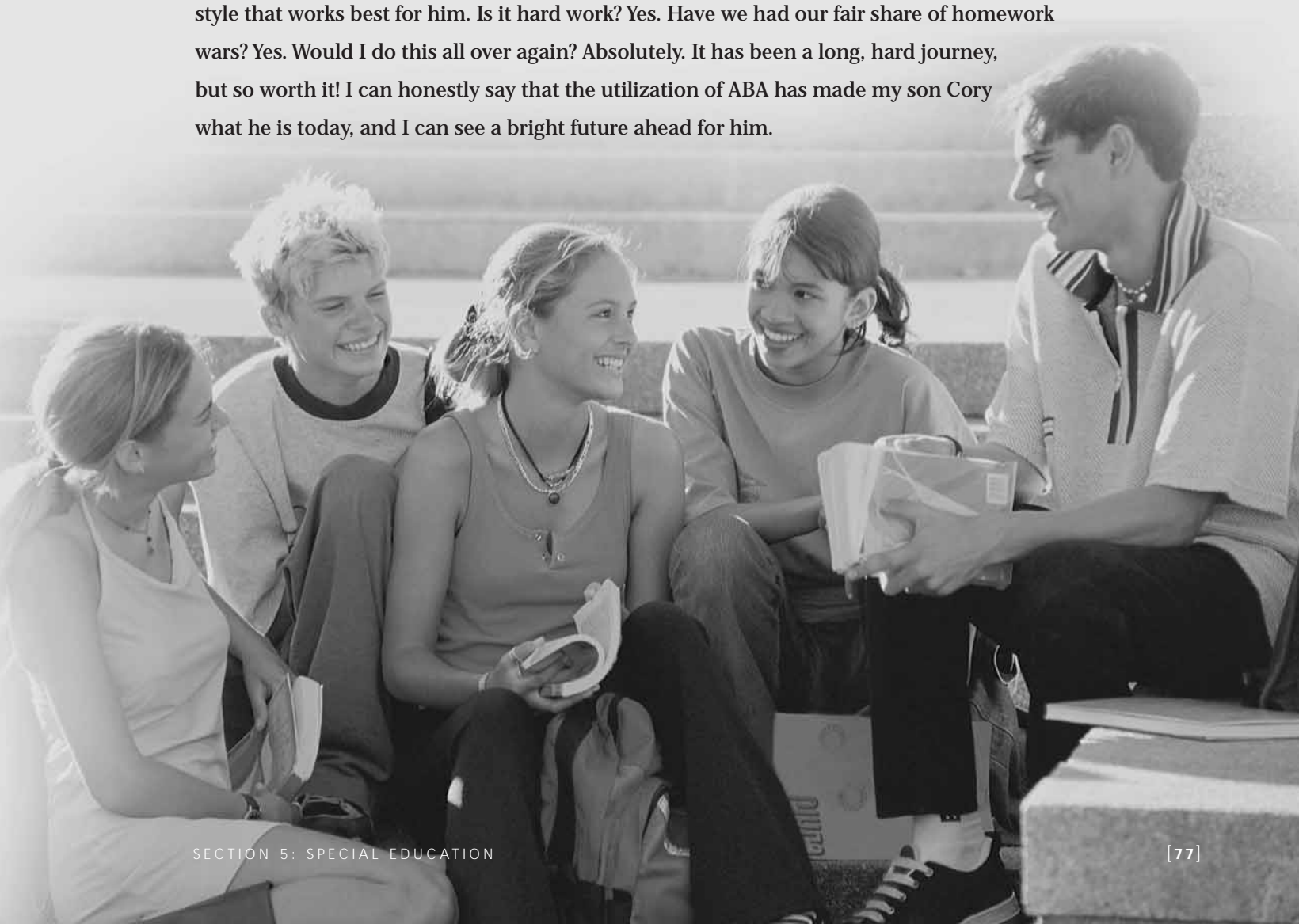
When my only son was diagnosed with an ASD, I spent the first six months in denial. I then realized that I needed to give up the career that I loved and devote myself to helping my child. I immediately began to seek out the interventions I could find for my son. Lucky for us, I researched a methodology entitled ABA (Applied Behavior Analysis), a data-based approach to developing skills and addressing the needs of individuals with ASD. Basically this is an intensive program which teaches everything a child needs to learn by breaking it down into the smallest possible increments and presenting it to the child through repetitive trials utilizing lots of positive reinforcement. From the age of 3 to 5, my son received 35 plus hours a week of ABA. The progress he made was nothing shy of miraculous. I felt like I was getting my child back.

It was my goal to get my child prepared to enter kindergarten with his typically-developing peers. Because Cory had made such extraordinary progress in his ABA program, I had every reason to believe that this was an achievable goal. Cory entered a typical kindergarten with support. He had a daily regimen of school in the morning and therapy in the afternoon and was still making substantial progress. To make the transition to a full day in first grade, it was decided to put Cory in a self-contained classroom with the end result of transitioning him into full inclusion by the end of the first grade. He was so successful that he was fully mainstreamed by March of that year. The key to his success was having a trained teaching assistant work with him and a special educator to oversee his IEP.

We followed this model for 1st and 2nd grade. The biggest hurdle we faced was Cory's attention deficit emanating from his ASD. Once he hit 3rd grade and the school work became more demanding, things began to unravel for Cory. I began to realize just how severe his reading comprehension deficit was. It became apparent that for Cory to succeed, he would need a great deal of modifications made to the curriculum, tests, class work, etc. I knew that I had to form a partnership with Cory's resource teachers and regular education teachers. I had to work very hard advocating for Cory to ensure that he had the necessary modifications he needed in order to be successful in the regular education placement. It took many IEP meetings and a lot of perseverance to finally get an IEP that would appropriately address his needs.

Today Cory is a teenager who attends the neighborhood public school and is fully included with the support of a trained teaching assistant. He has maintained excellent grades in school and we are extremely proud of him. He goes to school dances, sings in the chorus, and is a very talented piano player. Cory also goes fairly regularly to the YMCA Teen Center and enjoys playing video games and pool with his peers. He is an avid Red Sox fan and is totally addicted to American Idol. Cory still receives HBTS services, where we are working on improving his social skills and instilling a better understanding of perspective taking.

It has been an arduous process to keep Cory in a regular education placement. I spend a lot of time using the ABA method to help him with his homework—breaking things down to the smallest pieces and using repetition and constant positive reinforcement. This is the learning style that works best for him. Is it hard work? Yes. Have we had our fair share of homework wars? Yes. Would I do this all over again? Absolutely. It has been a long, hard journey, but so worth it! I can honestly say that the utilization of ABA has made my son Cory what he is today, and I can see a bright future ahead for him.



### *Transition Folder*

This printed file folder is designed to help students, parents, and teachers organize transition-related materials. The folder can be found at [www.ric.edu/sherlockcenter/publications/TranFolder.pdf](http://www.ric.edu/sherlockcenter/publications/TranFolder.pdf)

## VOCATIONAL/EMPLOYMENT TRANSITION

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The *Vocational Rehabilitation (VR) Program*, a subsidiary of ORS, is the public state and federally funded program that assists individuals with disabilities to choose, prepare for, obtain, and maintain employment. Individuals eligible for vocational rehabilitation services must meet the following qualifications: 1) have a physical or mental impairment which is a substantial barrier to employment, 2) require vocational rehabilitation services to prepare for, secure, retain, or regain employment, and 3) be able to benefit from vocational rehabilitation services in terms of an employment outcome. Individuals with disabilities must first apply for the VR program and be determined eligible before services can be provided. Individuals with significant disabilities are presumed eligible for the program if an application is completed and there is documentation of disability. The eligible individual with a disability and a Qualified Vocational Rehabilitation Counselor will work together to develop an employment plan called the Individualized Plan for Employment (IPE). The Employment Plan considers the individual's unique strengths, resources, priorities, concerns, skills, abilities, preferences, capabilities, interests, and values, as well as the barriers to employment.

Helpful resource information on employment opportunities is provided by the Rhode Island Department of Labor and Training at [www.dlt.ri.gov](http://www.dlt.ri.gov). Of particular interest for students are the one-stop employment centers where they can receive assistance with seeking employment, preparing a resume, or receiving unemployment or other worker benefits. See [www.networkri.org](http://www.networkri.org) for more information.

## HEALTHCARE TRANSITION

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The Rhode Island Department of Health, Office of Special Health Care Needs' Adolescent Healthcare Transition Program assists youth, families, physicians, schools, and other providers in the transition and transfer of youth with special healthcare needs from pediatric to adult healthcare. Rhode Island provides educational materials about the adolescent transition process through its state agencies.

### *Health Care Transition: Planning for Teens with Special Healthcare Needs*

This four page booklet for parents, caregivers, or professionals of youth with special healthcare needs describes the importance of healthcare transition and steps to take to



be ready. The document can be found at [www.health.ri.gov/publications/guidebooks/HealthCareTransitionPlanningForTeensWithSpecialHealthCareNeeds.pdf](http://www.health.ri.gov/publications/guidebooks/HealthCareTransitionPlanningForTeensWithSpecialHealthCareNeeds.pdf)

*Adolescent Healthcare Transition Parent Brochure*

This one page brochure for parents of youth with special healthcare needs describes the steps to increase independence in youth. The document can be found at [www.health.ri.gov/brochures/specialneedschildhoodtransition/GraduateToAdulthoodHowHealthcareTransitionWorksForParentsAndCaregivers.pdf](http://www.health.ri.gov/brochures/specialneedschildhoodtransition/GraduateToAdulthoodHowHealthcareTransitionWorksForParentsAndCaregivers.pdf)

*Youth with Disabilities, Chronic Conditions, or Special Healthcare Needs Student Brochure*

This one page brochure for youth with special healthcare needs introduces the concept of healthcare transition and discusses its importance. The document can be found at [www.health.ri.gov/brochures/specialneedschildhoodtransition/ReadySetGoGraduateToAdulthoodHowHealthcareTransitionWorksAGuideForTeens.pdf](http://www.health.ri.gov/brochures/specialneedschildhoodtransition/ReadySetGoGraduateToAdulthoodHowHealthcareTransitionWorksAGuideForTeens.pdf)

*My Life, My Health Checklists: Ready, Set, Go Series*

This three part self-assessment series helps youth and their families prepare for the healthcare transition. Checklists include knowledge of the condition and medical history, locating and interviewing an adult healthcare provider, and more. The documents can be found at:

- » [www.health.ri.gov/brochures/specialneedschildhoodtransition/ready.pdf](http://www.health.ri.gov/brochures/specialneedschildhoodtransition/ready.pdf)
- » [www.health.ri.gov/brochures/specialneedschildhoodtransition/getset.pdf](http://www.health.ri.gov/brochures/specialneedschildhoodtransition/getset.pdf)
- » [www.health.ri.gov/brochures/specialneedschildhoodtransition/go.pdf](http://www.health.ri.gov/brochures/specialneedschildhoodtransition/go.pdf)

Easy to follow checklist instructions for providers, parents, and caregivers can be found at [www.health.ri.gov/brochures/specialneedschildhoodtransition/InstructionsMyLifeMyHealth.pdf](http://www.health.ri.gov/brochures/specialneedschildhoodtransition/InstructionsMyLifeMyHealth.pdf)

*Portable Medical Summary*

This one page document provides a summary of important pediatric diagnoses, services, and treatments that would be critical for an adult healthcare provider to know for continuity of care. The document can be found at [www.health.ri.gov/forms/medical/PortableSummary.doc](http://www.health.ri.gov/forms/medical/PortableSummary.doc)

*Benefits at a Glance*

This chart outlines assistance programs available in Rhode Island for adults with disabilities. It can be found at <http://adrc.ohhs.ri.gov/benefits/index.php>

# Ondrea's Story

***Ondrea, a woman living with an ASD, provided her recollection of what it is like to live as an adult with an ASD.***

Hi, everyone. My name is Ondrea, and I am 24 years old. I am the Residential Services Secretary for an agency in Rhode Island. I've been there since December 12, 2001, where I first started out as a receptionist. The reason I'm writing this is because I'm autistic. I was diagnosed at Bradley Hospital in East Providence with mild autism because my behavior wasn't normal. When I went to school in my younger days, temper tantrums started in the classroom, and I would get disciplined. In my later years, I would go to counseling to sort out my feelings about different issues.

But then again, I'm not your typical autistic person. It is said that a lot of autistic people do not make friends or socialize. I'm one of those exceptions because I like to meet people, and I do have some friends. I taught myself how to read and write when I was three years old. I did pretty well in school, especially in high school (I was in a regular education homeroom starting in the seventh grade, but I still went to Resource for assistance) and being on the honor roll every quarter. I ended up being on the National Honor Society, and I was one of the top twenty-three students in 1999.

Just because my grades were great didn't mean my socializations with some of my fellow classmates were! There were several of them who did not understand when they put me down. In the eleventh grade, I received detention for forging a teacher's signature on a pass to go to the bathroom. Some of the students ended up telling the teachers what I did, and I was upset about that. However, I did go to detention so I wouldn't be suspended!

College was the same way. I had a B-plus average at the Sawyer School in 1999–2000 in Woonsocket. My classes were fairly easy (with the exception of a C in Records Management) with A grades most of the way, but some of my college students ridiculed me, too! (Usually, college students are supposed to act their age!) In my case, a lot of immature people failing had to make my life a bit hard because I was passing! The teachers, however, were more understanding and caring, as I even presented work on autism in one or two classes.

Autism is an often-misunderstood disorder because it seems like everyone is not informed. People who are autistic can understand their own world, but others who are not autistic can't. I'd like to be a voice for all autistics all over the world so they can understand where I'm coming from. I may be different from other people, but that won't stop them from being supportive of what I do. It is time that a person with autism speaks and everyone else needs to listen.

# Community Resources and Websites

The complexity of symptoms and needs that affect an individual with an Autism Spectrum Disorder (ASD) also impact the family. In addition to treatment and education for the child with an ASD, family support, parent training, in-home therapy, advocacy, and other support services are critical components of overall treatment of an ASD. It is important that families of children with special healthcare needs, including ASDs, have a strong support network of community resources. Fortunately, there are a number of resources available in Rhode Island for children with ASDs as well as for their families.

Understanding the different services that each community agency or organization provides allows families to access the services that meet the specific needs of their children.

This section of the guide provides a listing of some of the community supports and websites that are available locally. The organizations listed in this section can be contacted by mail or by telephone. If you have a computer, you can access a great deal of information on their websites. Many of these organizations have up-to-date information on ASDs.



# Summary of Rhode Island Community Resources by Type of Service

Below is a summary table of community resources available in Rhode Island, organized by type of service(s) provided. This table is provided to help you quickly identify appropriate agencies for the kind of service(s) or support that you or your child with an ASD needs. The next section, Alphabetical List of Rhode Island Community Resources, starting on page 84, provides a full description of and contact information for each agency listed in the table.

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EVALUATION, ASSESSMENT, DIAGNOSIS	» Bradley Hospital (page 85) » CEDARR Family Centers (page 85) » The Children's Neurodevelopment Center at Rhode Island Hospital (page 88) » Early Intervention Programs (page 89) » The Groden Center, Inc. (page 92) » NeuroDevelopment Center (page 96) » Neurodevelopmental Center of Memorial Hospital (page 96)
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*See Sections 2 and 4 for more information about Evaluation, Assessment, and Diagnosis.*

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SERVICE COORDINATION/ RESOURCE CENTERS	» The Autism Project (page 84) » CEDARR Family Centers (page 85) » Early Intervention Programs (page 89) » The Groden Center, Inc. (page 92) » Paul V. Sherlock Center on Disabilities at Rhode Island College (page 99) » Pediatric Practice Enhancement Project (PPEP) (page 99) » Peer Assisted Health Initiative (PAHI) (page 101) » Rhode Island Parent Information Network (RIPIN) (page 103)
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SUPPORT FOR PARENTS AND FAMILIES, INCLUDING TRAINING, ADVOCACY, AND RESEARCH	» The Autism Project (page 84) » Autism Society of America—Rhode Island Chapter (page 84) » Families for Effective Autism Treatment (FEAT) (page 91) » Family Voices of Rhode Island at Rhode Island Parent Information Network (page 103) » Parent Support Network of Rhode Island (PSN) (page 97) » Paul V. Sherlock Center on Disabilities at Rhode Island College (page 99) » Rhode Island Developmental Disabilities Council (page 103) » Rhode Island Parent Information Network (RIPIN) (page 103)
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- » The Sensational Child (page 106)
- » Siblink Program (page 107)
- » TechACCESS of Rhode Island (page 107)

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**EDUCATION**

- » Early Intervention Programs (page 89)
- » Other Educational Settings (page 113)

*See Section 3 for more information on Early Intervention Programs.*

*Section 5 for more information on Education Services.*

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**TREATMENT AND**

**THERAPEUTIC SERVICES**

- » Bradley Hospital (page 85)
- » Early Intervention Programs (page 89)
- » The Groden Center, Inc. (page 92)
- » Home-Based Therapeutic Services (HBTS) (page 95)
- » Kids Connect (page 95)
- » Meeting Street (page 95)
- » Pathways Strategic Teaching Center (page 99)
- » Personal Assistant Services and Supports (PASS) (page 102)

*See Section 4 for more information on treatment and interventions.*

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**THERAPEUTIC RECREATION**

- » Greenlock Therapeutic Riding Center (page 110)
- » Sail to Prevail (page 111)
- » Special Olympics (page 112)

*See page 108 for a list of playgrounds and other recreational programs for children with special healthcare needs.*

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**TRANSPORTATION SERVICES**

- » Ocean State Center for Independent Living (OSCIL) (page 97)
- » PARI Independent Living Center (page 98)
- » RIPTA Ride Share Program (page 106)

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**LEGAL ASSISTANCE/ADVOCACY**

- » Advocates in Action (page 84)
- » Commission for Human Rights (page 102)
- » Rhode Island Disability Law Center (page 103)

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**VOCATIONAL ASSISTANCE/  
TRANSITIONAL SERVICES**

- » The Autism Project (page 84)
- » The Groden Center, Inc. (page 92)
- » Office of Rehabilitation Services (page 97)
- » Regional Transition Centers (page 104)
- » Rhode Island Technical Assistance Project at the Department of Education (page 105)

*See Section 5 for more information on transitional services.*

# Alphabetical List of Rhode Island Community Resources

## ADVOCATES IN ACTION

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Advocates in Action is Rhode Island's statewide self-advocacy group.

PO Box 41528, Providence, RI 02940

Phone: (401) 785-2028

TTY: (800) 745-5555

Website: [www.aina-ri.org](http://www.aina-ri.org)

## THE AUTISM PROJECT

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The Autism Project is a unique collaboration of families and professionals whose mission is to create a comprehensive system of services to support individuals with ASDs, their families, and the professionals who support and educate them. The Autism Project achieves this mission by providing social skill groups, a two-week summer camp, a Volunteer/Mentoring program for teens with Asperger Syndrome, multiple levels of training for families and professionals, classroom consultations, workshops, a National Speaker Conference, and by supporting demonstration classrooms for teachers and professionals to visit to view best practices in action. The Autism Project also offers a Family Training and Support Center for families of children with ASDs. This project is supported by the Rhode Island Department of Health with funds from the Department of Health and Human Services' State Implementation Grant for Improving Services for Children and Youth with ASD.

1516 Atwood Avenue, Johnston, RI 02919

Phone: (401) 785-2666

Website: [www.theautismproject.org](http://www.theautismproject.org)

## AUTISM SOCIETY OF AMERICA—RHODE ISLAND CHAPTER

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The Rhode Island chapter of the Autism Society of America was established in November 2005. Goals include enhancing community awareness, acceptance, and participation of individuals with ASD; keeping updated on legislative activity; and maintaining a supportive, informative network comprised of families, teachers, and community leaders. Chapter activities include community awareness, advocacy, and fund raising.

PO Box 16603, Rumford, RI 02916

Phone: (401) 595-3241

Website: [www.autism-society.org](http://www.autism-society.org)

## BRADLEY HOSPITAL

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Bradley Hospital is a not-for-profit hospital that serves children and adolescents that have behavioral, developmental, emotional, and psychological problems. A Lifespan partner and Brown Medical School affiliate, Bradley has established itself as the national center for training and research in child and adolescent psychiatry. Services at Bradley Hospital include the following:

- » Evaluation and assessment for ASD
- » Inpatient services, ages 2–18
- » Residential services, ages 5–12
- » Outpatient services, psychiatric and therapeutic
- » Emergency services, 24 hours a day
- » Crisis services, evaluation and referral
- » Developmental Disabilities Program, ages 4–22
- » Special Education services, ages 3–21 (a referral is made through your local school department)

1011 Veterans Memorial Parkway, East Providence, RI 02915

Phone: (401) 432-1000

Fax: (401) 432-1500

Website: [www.bradleyhospital.org](http://www.bradleyhospital.org)

## CEDARR FAMILY CENTERS

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CEDARR stands for Comprehensive Evaluation, Diagnosis, Assessment, Referral, and Re- with special needs. Through a CEDARR Family Center a family can learn more about their child's disability/condition, how to Address their child's needs, find community resources, get information on a range of services/treatment options, and connect with other families.

To be eligible for CEDARR Family Center services, a child must be eligible for Medical Assistance, younger than 21 years old, a Rhode Island resident living at home, and have a disabling or chronic condition that is cognitive, physical, developmental, and/or psychiatric. The following services may be available for eligible CYSHCN serviced through CEDARR Family Centers: Home Based Therapeutic Services (HBTS), Personal Assistance Services and Supports (PASS), Kids Connect, and Respite. There are four CEDARR Family Centers that serve families statewide:

### About Families CEDARR Center

203 Concord Street, Suite 335, Pawtucket, RI 02860

Phone: (401) 365-6855 or 1-877-365-6024

Website: [www.aboutfamilies.org](http://www.aboutfamilies.org)

#### Elmhurst School Site

1 Frank Coelho Drive, Portsmouth, RI 02871

Phone: (401) 365-6855 or 1-877-365-6024

Website: [www.aboutfamilies.org](http://www.aboutfamilies.org)

#### Empowered Families CEDARR Center

82 Pond Street, Pawtucket, RI 02860

Phone: (401) 365-6103 or (888) 881-6380

Website: [www.empoweredfamilies.org](http://www.empoweredfamilies.org)

#### Families First CEDARR Center

765 Allens Avenue, 1st Floor, Providence, RI 02905

Phone: (401) 444-7703

#### Solutions CEDARR Center

134 Thurbers Avenue, Suite 102, Providence, RI 02905

Phone: (401) 461-4351 or (800) 640-7283

Website: [www.solutionscedarr.org](http://www.solutionscedarr.org)

#### Lafayette Mills Site

610 Ten Rod Road, Unit 13, North Kingstown, RI 02852

Phone: (401) 461-4351 or (800) 640-7283

Website: [www.solutionscedarr.org](http://www.solutionscedarr.org)

#### CHILD AND ADOLESCENT INTENSIVE TREATMENT SERVICES

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The Child and Adolescent Intensive Treatment Services (CAITS) Program provides intensive treatment to children and adolescents with serious emotional and behavioral problems who are at risk for being placed in a psychiatric hospital or residential care. CAITS is a short-term program that is delivered both in the child or adolescent's home and community setting.

#### Child and Family Services

31 John Clarke Road, Middletown, RI 02842

Phone: (401) 845-8921

Fax: (401) 608-1841

Website: [www.childandfamilyri.com](http://www.childandfamilyri.com)

#### East Bay Center: Adams Farley Counseling Center

610 Wampanoag Trail, East Providence, RI 02915

Phone: (401) 431-9870 ext. 103

Fax: (401) 435-7486

Website: [www.eastbay.org](http://www.eastbay.org)



**Family Service of Rhode Island**

55 Hope Street, Providence, RI 02906

650 Ten Rod Road, Unit 13, North Kingstown, RI 02852

Phone: (401) 519-2277

Fax: (401) 854-0012

Website: [www.familyserviceri.org](http://www.familyserviceri.org)

**Gateway Healthcare, Inc.**

160 Beechwood Avenue, Pawtucket, RI 02860

1471 Elmwood Avenue, Cranston, RI 02910

Phone: (401) 729-8701

Fax: (401) 726-5571 (Pawtucket) or (401) 490-7694 (Cranston)

Website: [www.gatewayhealth.org](http://www.gatewayhealth.org)

**The Kent Center for Human and Organizational Development**

2756 Post Road, Suite 104, Warwick, RI 02886

Phone: (401) 691-6000 ext. 327

Fax: (401) 738-7718

Website: [www.thekentcenter.org](http://www.thekentcenter.org)

**Newport Community Mental Health Center**

26 Valley Road, Middletown, RI 02842

Phone: (401) 848-6363 ext. 130

Fax: (401) 848-6389

**Northeast Behavioral Associates**

Airport Professional Park

2348 Post Road, Suite 107, Warwick, RI 02886

Phone: (401) 681-4637 ext. 104

Fax: (401) 681-4675

Website: [www.northeastbehavioral.com](http://www.northeastbehavioral.com)

**NRI Community Services, Inc.**

181 Cumberland Street, Woonsocket, RI 02895

Phone: (401) 235-7400

Fax: (401) 767-9107

Website: [www.nricommunityservices.org](http://www.nricommunityservices.org)

**The Providence Center**

520 Hope Street, Providence, RI 02906

Phone: (401) 276-4161

Fax: (401) 276-4571

Website: [www.provctr.org](http://www.provctr.org)

**Psychological Centers, Inc.**

765 Allens Avenue, Suite 102, Providence, RI 02905

Phone: (401) 490-8915

Fax: (401) 490-2619

Website: [www.psychologicalcenters.com](http://www.psychologicalcenters.com)

**South Shore Mental Health Center**

55 Cherry Lane, Wakefield, RI 02879

Phone: (401) 789-1367 ext. 3157

Fax: (401) 789-6744

Website: [www.ssmhc.org](http://www.ssmhc.org)

**CHILDHOOD COMMUNICATION SERVICES**

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Childhood Communication Services provides consultation and program evaluation services to schools and other agencies serving children with ASDs and related disabilities, and for families. The Program uses the SCERTS™ Model. (See Section 4 for more information.)

35 Kent Place, Cranston, Rhode Island 02905

Website: [www.barryprizant.com/childhood\\_communication\\_services.htm](http://www.barryprizant.com/childhood_communication_services.htm)

**THE CHILDREN'S NEURODEVELOPMENT CENTER AT RHODE ISLAND HOSPITAL**

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**(FORMERLY KNOWN AS THE CHILD DEVELOPMENT CENTER)**

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The Children's Neurodevelopment Center (CNDC) at Hasbro Children's Hospital is a site for the evaluation and treatment of children with neurological, genetic, metabolic, and behavioral disorders. The Center utilizes a team approach that allows for coordination between specialists for evaluation, assessment, and diagnosis. The CNDC is staffed with specialists in the areas of education, nutrition, genetics, developmental pediatrics, neurology, psychology, nursing, and social services. Consults from other pediatric specialists are also available, including neurosurgery, orthopedics, urology, and otolaryngology. Initial referral of a child to the CNDC should be made by the child's primary care physician.

Evaluation, diagnosis, and treatment recommendations, once completed, are discussed with and provided in a written report for the family. The report can be made available (with family permission) to physicians, schools, and other agencies that may be involved with the child.

The CNDC also provides ongoing medical care for children with ASDs and other neurodevelopmental disabilities.

593 Eddy Street, Providence, RI 02903

Phone: (401) 444-5685

Fax: (401) 444-6115

Website: [www.lifespan.org/hch](http://www.lifespan.org/hch)

#### **EARLY INTERVENTION PROGRAMS**

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Each state is mandated to provide an Early Intervention (EI) program for children with developmental delays (birth to three years of age) in accordance with a federal law entitled the Individuals with Disabilities Education Act (IDEA). In Rhode Island, the Rhode Island Department of Human Services administers the EI program.

EI is a family-centered program that promotes the growth and development of infants and toddlers with developmental challenges. EI serves all eligible children (birth to age three years of age) and their families, regardless of income or health insurance coverage. All EI sites provide services to children with ASDs and their families. Services are individualized to support and assist families in meeting the goals that they have for their children. Referrals for a child who has an ASD or symptoms of an ASD can be made directly to EI programs by family members, guardians, primary care physicians, and community agencies for infant and toddler screening, evaluation, and assessment to determine eligibility for services.

#### **Children's Friend and Service**

621 Dexter Street, Central Falls, RI 02863

Phone: (401) 721-9200

Fax: (401) 729-0010

Website: [www.cfsri.org](http://www.cfsri.org)

#### **Easter Seals**

213 Robinson Street, Wakefield, RI 02879

Phone: (401) 284-1000

Fax: (401)284-1006

Website: [www.eastersealsri.com](http://www.eastersealsri.com)

#### **Family Resources Community Action**

245 Main Street, Woonsocket, RI 02895

Phone: (401) 766-0900

Fax: (401) 766-8737

Website: [www.famresri.org](http://www.famresri.org) (look under "Programs and Services")

**Family Service of Rhode Island**

134 Thurbers Avenue, Providence, RI 02905

Phone: (401) 331-1350

Fax: (401) 277-3388

Website: [www.familyserviceri.org](http://www.familyserviceri.org)

**Hasbro Children's Hospital**

765 Allens Avenue, 1st Floor, Providence, RI 02905

Phone: (401) 444-3201

Fax: (401) 444-8507

Website: [www.lifespan.org/partners/hch](http://www.lifespan.org/partners/hch)

**Homestead Group**

One Cumberland Plaza, 3rd Floor

Woonsocket, RI 02895

Phone: (401) 775-1500

Fax: (401) 762-0837

Website: [www.thgri.org](http://www.thgri.org)

**J. Arthur Trudeau Memorial Center**

*Kent County*

250 Commonwealth Ave

Warwick, RI 02886

Phone: (401) 823-1731

Fax: (401) 823-1849

Website: [www.trudeaucenter.org](http://www.trudeaucenter.org)

*South County*

125 West Independence Way, Suite N

Kingston, RI 02881

Phone: (401) 284-1980

Fax: (401) 284-1979

Website: [www.trudeaucenter.org](http://www.trudeaucenter.org)

**James L. Maher Center**

120 Hillside Avenue

Newport, RI 02840

Phone: (401) 848-2660

Fax: (401) 847-9459

Website: [www.mahercenter.org](http://www.mahercenter.org)

**Looking Upwards, Inc.**

2974 East Main Road

Portsmouth, RI 02871

Phone: (401) 293-5790

Fax: (401) 293-5795

Website: [www.lookingupwards.org](http://www.lookingupwards.org)

**Meeting Street**

1000 Eddy Street

Providence, RI 02905

Phone: (401) 533-9100

Fax: (401) 533-9102

Website: [www.meetingstreet.org](http://www.meetingstreet.org)

### *The Groden Early Intervention Center*

If your child has symptoms of autism or a diagnosis of an ASD, the EI site you select may refer your child to the Groden EI Center. The Groden Center, Inc., founded in 1976, is a non-profit agency that serves individuals of all ages with ASDs. The Groden Center EI program is the only EI site in Rhode Island that is designed to work specifically with children with ASDs. The Groden Center does not provide families and children with full services, but works with an EI full-service provider to coordinate all needed services.

86 Mount Hope Avenue, Providence, RI 02906

Phone: (401) 274-6310

Fax: (401) 421-3280

Website: [www.grodencenter.org](http://www.grodencenter.org)

See page 92 for more information about the Groden Center.

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### **FAMILIES FOR EFFECTIVE AUTISM TREATMENT**

Families for Effective Autism Treatment (FEAT) of Rhode Island is a non-profit organization of families. Their mission is to inform families, professionals, and the community about effective science-based treatment of ASDs. FEAT strives to disseminate accurate information about ASDs, promote the development of quality programs, and guide, support, and advocate for families seeking this type of intervention. In addition to supporting families, FEAT offers an annual conference, a guest speaker series throughout the year, and a lending library.

5 Crane Terrace, Narragansett, RI 02882

Phone: (401) 886-5015

Fax: (401) 739-7384

Email: [featr@gmail.com](mailto:featr@gmail.com)

Website: [www.featri.org](http://www.featri.org)

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### **FAMILY CARE COMMUNITY PARTNERSHIPS**

Four regional Family Care Community Partnerships (FCCPs) (Urban Core, Northern, West Bay, and East Bay) consolidate the management of the Department of Children, Youth, and Families (DCYF) prevention, early intervention, and community-based behavioral health programs in order to integrate and expand services and supports for each child and family according to their unique strengths and needs. The FCCP provides a system of care approach for families with children and youth who are at risk for DCYF involvement due to abuse and neglect or Serious Emotional Disturbance (SED) and youth who are returning to the community following a Rhode Island Training School sentence. Further information about the FCCPs can be found at [www.dcyf.ri.gov](http://www.dcyf.ri.gov)

Urban Core (Lead Agency)

Family Service

134 Thurbers Avenue, Providence, RI 02905

Phone: (401) 331-1350

(Partner Agencies: John Hope, Children's Friend and Service, TIDES  
Family Services, Providence Center, Cranston Community Action)

Northern (Lead Agency)

Family Resources Community Action

245 Main Street, Woonsocket, RI 02895

Phone: (401) 766-0900

(Partner Agencies: Comprehensive Community Action, Northern Rhode Island  
Community Services, Gateway Healthcare)

West Bay (Lead Agency)

South County Community Action

1935 Kingstown Road, Wakefield, RI 02897

Phone: (401) 789-3016

(Partner Agencies: Family Service of Rhode Island, Westbay Community Action, Thundermist  
Health Centers, Wood River Health Center, WellOne Family Health North Kingston)

East Bay (Lead Agency)

Child and Family Services of Newport

24 School Street, Newport, RI 02842

Phone: (401) 849-2300

(Partner Agencies: East Bay Community Action, East Bay Center,  
Newport County Mental Health)

THE GRODEN CENTER, INC.

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The Groden Center, Inc., the largest provider in Rhode Island of services dedicated to individuals with ASDs, was founded in 1976 with a mission to support, teach, nurture, and challenge individuals with ASDs to reach their greatest level of independence, productivity, and participation in their communities. A variety of programs accomplish this goal by providing the most effective educational and therapeutic services, by advancing knowledge and best practices through research, education, and training, and by involving, educating, and supporting families in caring for and advocating for their children.

The following list of programs offered by the Groden Center reflects the continuum of supports that have been developed to meet the variety of needs of individuals with ASDs throughout their lifespan.

**The Community Support Services (CSS) Department** provides on-site evaluation, treatment, training, and consultation services to schools, group homes, families, and other agencies or treatment providers involved in the assessment and treatment of children and adults with developmental and/or behavioral disabilities. Direct treatment services in the form of individual or group-based skills development training are also provided in school settings. The CSS department also offers group therapy services for individuals with social disabilities during the summer months. A social club and therapy group is available throughout the school year for young adolescents with Asperger Disorder. Diagnostic, psychological, and behavioral evaluations are also conducted through the CSS department.

**The Groden Center Day School** serves children between the ages of 3 and 21 from Rhode Island and neighboring states. It operates 12 months a year and provides instruction in functional skill development, communication, emotional and social development, physical and recreational skills, and vocational education. The school also runs a Saturday therapeutic recreation program.

**The Groden Center's Early Intervention Program (EIP)** is part of a statewide network of regional EI programs and specializes in working with infants and toddlers with ASD diagnoses. Services, which must be accessed through the full service EI provider, include home visiting, playgroups, and parent support groups.

**Home-Based Treatment Services** are supplied through two programs: Children's Intensive Treatment (CIT) and In-home Support and Training (IST). CIT offers structured learning opportunities for children from 3–6 years of age who have morning and/or early afternoon hours available for therapy in their homes. The goal of the program is to prepare children behaviorally and academically for placement in the least restrictive school setting possible. IST services provide assistance with behavior therapy and instructional strategies in homes and relevant community settings to children ages 7–21 and families. Families are taught practical behavioral strategies that are effective with their children; children are taught functional skills and coping strategies to gain self-control and to foster independence. Children helped through IST services are typically challenged by serious behavioral concerns related to ASDs. Referrals to home-based treatment services must originate through a CEDARR Family Center.

**The Livingston Center Preschool and Daycare Center** opened in 1998 with the purpose of fully integrating children of differing abilities. At capacity, the preschool can serve 20 children, 6 of whom are typically children with disabilities. The preschool program emphasizes ongoing, individualized assessment of progress by an interdisciplinary team, communication with families, and a one-to-one balance of small group and large group activities.

**The Professional Family Living Arrangement (PFLA)** program is a therapeutic foster care program working to keep children and youth in home settings while providing intensive and highly specialized behavioral and therapeutic services. PFLA handles short- and long-term placement of children and youth with challenging behaviors and developmental disabilities through the Department of Children, Youth, and Families.

**Residential Programs** are available for adolescent students of the Day School who are in need of alternative living arrangements. There are currently 4 homes serving 17 boys and 3 girls in residences located in both suburban and rural settings.

**The Vocational Training and Employment Program** assists individuals in discovering their employment interests and aptitudes. This program offers a variety of assessment and training activities, can include job coaching, and may lead to part-time or full-time employment. It can be done on a part-time or full-time basis and in coordination with other educational or support services.

The Groden Center participates in selected research activities and provides adult programs, both day and residential, in Massachusetts (The Halcyon Program) and Rhode Island (The COVE Center).

86 Mount Hope Avenue, Providence, RI 02906

Phone: (401) 274-6310

Fax: (401) 421-3280

Website: [www.grodencenter.org](http://www.grodencenter.org)





#### HOME-BASED THERAPEUTIC SERVICES

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Home-Based Therapeutic Services (HBTS) are a CEDARR direct service for children living at home who have Medical Assistance coverage and have been diagnosed with moderate to severe physical, developmental, behavioral, or emotional conditions. Specialized services are provided in accordance with an approved individualized treatment plan. The goal of this service is to enhance the child's ability to participate within the family and community. Enhanced HBTS allow families of children waiting for HBTS to receive some intervention services prior to specialized treatment. HBTS are accessed through CEDARR Family Centers.

#### KIDS CONNECT

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Kids Connect is a CEDARR direct service that provides therapeutic services delivered in licensed child care centers for certain Medical Assistance eligible children and youth (6 weeks to 19 year of age) with serious behavioral, developmental, healthcare, or physical needs. The purpose of Kids Connect is to enable children and youth with special health care needs to participate in child and youth care settings with their peers. This service is designed as a less restrictive and more inclusive alternative or complementary service to HBTS. Kids Connect services are accessed through CEDARR Family Centers.

#### MEETING STREET

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Meeting Street offers children and families a personalized and comprehensive approach to making the most of important times in a child's growth and development. Founded in 1946, Meeting Street helps children and young adults with special healthcare needs and their families meet the challenges in their lives.

Meeting Street services encompass all areas of development, including communication, motor and planning skills, social skills, and health and family needs. Understanding that every family is unique, Meeting Street staff work with children to apply interventions into their everyday routines and integrate learning into their natural environments. Specialized Services for children with ASDs and other social communication disorders include:

**The Early Intervention (EI) Program** provides evaluations, therapeutic services, and support for children from birth to age three and for their families. The largest provider of EI services in Rhode Island, Meeting Street offers children and families a highly personalized, comprehensive, and kindhearted approach to this very important step in early development.

**More Than Words—The Hanen Program for Parents of Children with Autism Spectrum Disorders** is an eleven-week program that teaches families practical tools to help children learn to communicate.

**Therapeutic Listening** is a technique that uses sound stimulation through music, in combination with Sensory Integration treatment techniques, to decrease sensory defensive behaviors, increase attention span, calm and organize thoughts, and improve communication.

**Sensory Integration Therapy** involves therapists working with families in their homes to help them understand sensory issues and how they affect their children, and to teach them how to use specific techniques in daily routines.

**Picture Exchange Communication Systems** are used to teach nonverbal children with ASDs communication skills. Children are taught to identify symbols and to use them to communicate instead of spoken language.

1000 Eddy Street, Providence, RI 02905

Phone: (401) 533-9100

Fax: (401) 533-9101

Website: [www.meetingstreet.org](http://www.meetingstreet.org)

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#### NEURODEVELOPMENT CENTER

The NeuroDevelopment Center is a private, multi-disciplinary center that provides traditional and innovative assessment and intervention options for children and adults with neurologically based conditions. These conditions may include Attention Deficit Hyperactivity Disorder (ADHD), Anxiety, Autism Spectrum Disorders (ASDs), Obsessive Compulsive Disorder (OCD), learning disabilities, behavioral problems, and other neurological difficulties.

260 West Exchange Street, Suite 210, Providence, RI 02903

Phone: (401) 351-7779

Website: [www.neurodevelopmentcenter.com](http://www.neurodevelopmentcenter.com)

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#### NEURODEVELOPMENTAL CENTER OF MEMORIAL HOSPITAL OF RHODE ISLAND

The Neurodevelopmental Center is an internationally recognized program that treats children with behavioral, learning, and developmental disabilities. Promoting success for children is the program's goal. The professionals treat children with Tics & Tourette Syndrome, Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Pervasive Developmental Disorder, ASDs, Asperger Disorder, learning disabilities, Traumatic Brain Injury (TBI), Cerebral Palsy, Post Prematurity, and cancer or seizure disorders (on referral).

555 Prospect Street, Pawtucket, RI 02860

Phone: (401) 729-6200

Website: [www.mhriweb.org](http://www.mhriweb.org)

#### OCEAN STATE CENTER FOR INDEPENDENT LIVING

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The Ocean State Center for Independent Living (OSCIL) is a community-based resource center that helps transport individuals with long-term health issues to services and supports in the community. *Please note: for adults only.*

1944 Warwick Avenue, Warwick, RI 02889

Phone: (401) 738-1013 ext. 13

TTY: (401) 738-1015

Fax: (401) 738-1083

Website: [www.oscil.org](http://www.oscil.org)

#### OFFICE OF REHABILITATION SERVICES

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The Department of Human Services (DHS) Office of Rehabilitation Services (ORS) provides Rhode Islanders who have disabilities with a comprehensive program of rehabilitation, social, and independent living services. To fulfill its mission of empowering individuals with disabilities to choose, prepare for, obtain, and maintain employment, economic self-sufficiency, independence, and integration into society, ORS administers the following programs and services:

**Vocational Rehabilitation (VR)** is designed to assist individuals who have a disability, making it difficult for them to work, to choose, prepare for, find, and maintain employment.

**Disability Determination Services (DDS)** determine the medical eligibility of children and adults with disabilities who are applying for cash benefits under the federal program for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

**Assistive Technology Access Partnership (ATAP)** is designed to remove barriers and to increase access to assistive technology devices and services for individuals with disabilities.

40 Fountain Street, Providence, RI 02903

Phone: (401) 421-7005 (English) or (401) 272-8090 (Spanish)

TTY: (401) 421-7016

Fax: (401) 222-3574

Website: [www.ors.ri.gov](http://www.ors.ri.gov)

#### PARENT SUPPORT NETWORK OF RHODE ISLAND

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The Parent Support Network (PSN) is a statewide organization of families supporting families with children and youth who are at risk for or who have behavioral and/or emotional challenges. They provide support groups, telephone support, educational events, one-on-one assistance

with advocacy, and literature concerning education, mental health, parenting a child with special emotional or behavioral needs, juvenile justice, and substance abuse case support. Meetings are held in various areas across the state. Services are available in Spanish.

Crossroad Commons Plaza  
1395 Atwood Avenue, Suite 114, Johnston, RI 02919  
Website: [www.psnri.org](http://www.psnri.org)

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#### PARI INDEPENDENT LIVING CENTER

PARI is a private, not-for-profit, community-based agency whose programs and policies are determined by people with disabilities. The PARI staff works with people with any kind of disability to identify goals and to provide training, equipment, advocacy, and counseling to help them achieve their goals. PARI helps clients seek medical resources, transportation, housing, or ways of becoming involved in the community.

500 Prospect Street, Pawtucket, RI 02860  
Phone: (401) 725-1966 (Voice/TTY) or (401) 365-1839 (Spanish/Portuguese)  
Fax: (401) 725-2104  
Website: [www.pari-ilc.org](http://www.pari-ilc.org)

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#### PATHWAYS STRATEGIC TEACHING CENTER

Pathways Strategic Teaching Center is a comprehensive education and treatment program/school serving children with ASDs and related disorders in a site-based setting. Pathways' education and treatment strategies are based on the principles of Applied Behavior Analysis (ABA), an organized and systematic approach that has been demonstrated effective in building skills as well as in assessing and treating problem behavior. Individually-tailored curricula address speech and language, pre-academic and academic skills, daily living and self-care skills, play and social skills, and the treatment of challenging behavior. Pathways is fully certified by the Rhode Island Department of Education as a 230-day special education program for pre-school and elementary-aged children. Pathways Strategic Teaching Center is an affiliated program of the Trudeau Center, Kent County ARC.

The Trudeau Center  
3445 Post Road, Warwick, RI 02887  
Phone: (401) 739-2700 ext. 275  
Fax: (401) 732-8907  
Website: [www.trudeaucenter.org](http://www.trudeaucenter.org)

#### PAUL V. SHERLOCK CENTER ON DISABILITIES AT RHODE ISLAND COLLEGE

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The Sherlock Center, founded at Rhode Island College in 1993, is a University Center for Excellence in Developmental Disabilities (UCEDD). UCEDDs are designed to increase the independence, productivity, and community integration and inclusion of individuals with developmental disabilities. There are 67 UCEDD programs in the United States. This national network is administered through the US Department of Health and Human Services Administration on Developmental Disabilities.

The mission of the Sherlock Center is to promote membership of individuals with disabilities in school, work, and the community. In Rhode Island, the Sherlock Center partners with state and local government agencies, schools, institutions of higher education, and community agencies. Projects and initiatives offer training, technical assistance, service, research, and information sharing. SherlockCenter.org offers a convenient and easy way to access disability-related information and resources. Newsletters, guides, fact sheets, and other publications designed to help families, educators, and agencies are available from the site. The Sherlock Center also has a Resource Library with over 1,500 resources available for the general public to review or borrow. Materials include books, periodicals, and audio and video tapes pertaining to family support, education, inclusion, positive behavioral support, employment, and transition to adult life.

600 Mt. Pleasant Avenue, Providence, RI 02908

Phone: (401) 456-8072

TTY: (401) 456-8773

Fax: (401) 456-8150

Website: [www.sherlockcenter.org](http://www.sherlockcenter.org)

#### PEDIATRIC PRACTICE ENHANCEMENT PROJECT

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The Pediatric Practice Enhancement Project (PPEP) assists pediatric primary and specialty care practices, including private practices, specialty sites, community health centers, and hospital-based clinics, in providing a medical home for Children and Youth with Special Health Care Needs (CYSHCN) and their families. Family Resource Specialists (trained family members with personal experience navigating complex healthcare systems) are placed on-site to provide families with resources, peer-to-peer support, and connections to community-based services. The Family Resource Specialists are matched to meet the needs of the populations served by the practices to ensure the delivery of family-centered, culturally competent services. The PPEP has a comprehensive documentation/data system that facilitates the evaluation of

program outcomes, identification of statewide system barriers, and documentation of patterns and challenges faced by the families the PPEP serves.

The following sites participate in the PPEP:

**Autism Project**

1516 Atwood Avenue, Johnston, RI 02919

**Children's Neurodevelopment Center (CNDC)**

593 Eddy Street, Providence, RI 02903

**Community Asthma Program**

593 Eddy Street, Annex Building, Suite 314, Providence, RI 02903

**Dr. Robert Burke**

Hasbro Children's Hospital, Lower Level

353 Eddy Street, Providence, RI 02905

**Dr. Cheryl Flynn**

2 Wake Robin Road, Lincoln, RI 02865

**Dr. Susan Stuart**

45 Wells Street, Suite 201, Westerly, RI 02891

**Federal Hill House**

9 Courtland Street, Providence, RI 02909

**Hasbro Children's Rehabilitation**

Hasbro Children's Hospital

765 Allens Avenue, Providence, RI 02905

**Neonatal Follow-Up Clinic**

134 Thurbers Avenue, Suite 215, Providence, RI 02905

**Neonatal Intensive Care Unit**

Women and Infants Hospital

101 Dudley Street, Providence, RI 02903

**Neurodevelopment Center**

Memorial Hospital, Department of Pediatrics

555 Prospect Street, Pawtucket, RI 02860

Park Pediatrics, Inc.  
801 Park Avenue, Cranston, RI 02910

Samuels Sinclair Dental Center  
Rhode Island Hospital  
593 Eddy Street, Providence, RI 02903

Socio-Economic Development Center for Southeast Asians  
270 Elmwood Avenue, Providence, RI 02907

South County Pediatric Group, Inc.  
4979 Tower Hill Road, Wakefield, RI 02879

Transition Clinic  
Medicine/Pediatrics Primary Care Center  
593 Eddy Street, Physicians' Office Building #224, Providence, RI 02903

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**PEER ASSISTED HEALTH INITIATIVE**

The Peer Assisted Health Initiative (PAHI) enhances primary and specialty care sites in providing a patient-centered medical home for youth and adults with special healthcare needs. Peer Resource Specialists (individuals with personal experience navigating the adult healthcare and/or employment system) are placed on-site to support the transition of youth from pediatric to adult medicine and assist adults in accessing community services, independent living, and educational/vocational resources. Peer Resource Specialists receive comprehensive training in systems navigation, advocacy, and systems change to ensure consumer-directed practices are established and maintained and that services are culturally competent, coordinated, and community-based. The PAHI has a comprehensive documentation/data system that facilitates the evaluation of program outcomes, identification of statewide system barriers, and documentation of patterns and challenges faced by the individuals the PAHI serves.

The following sites participate in the PAHI:

Butler Hospital  
345 Blackstone Boulevard, Providence, RI 02906

Rhode Island Department of Corrections  
39 Howard Avenue, Cranston, RI 02920

The Rhode Island Free Clinic  
655 Broad Street, Providence, RI 02905

Rhode Island Hospital  
593 Eddy Street, APC Building, 5th Floor  
Room 570 (Medical Primary Care) or  
Room 552 (Medical Specialty)  
Providence, RI 02903

Rhodes to Independence  
14 Harrington Road, Barry Hall, Building 52, Room B-6, Cranston, RI 02920

St. Joseph's Health Center  
OB/GYN or Primary Care  
21 Peace Street, Providence, RI 02907

WellOne  
*North Kingston*  
308 Callahan Road, North Kingston, RI 02852

*Pascoag*  
6 Bridge Way, Pascoag, RI 02859

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#### PERSONAL ASSISTANCE SERVICES AND SUPPORTS

Personal Assistance Services and Supports (PASS) is a CEDARR direct service that provides consumer-directed services and supports for children with special healthcare needs who are Medical Assistance-eligible. In this program, the PASS worker is recruited and supervised by the family, who receives support from a PASS Family Support Agency. This service focuses on increasing the child's ability to accomplish activities of daily life, make self-preserving decisions, and participate in social roles and settings. The assistance provided to the child by the PASS worker includes hands-on assistance (performing a personal care task for a child) or cuing so that the child performs the task by him or herself. PASS Services are accessed through CEDARR Family Centers.

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#### THE RHODE ISLAND COMMISSION FOR HUMAN RIGHTS

The Commission for Human Rights educates the public on discrimination laws/issues and conducts objective investigations of charges filed.

10 Abbot Park Place, Providence, RI 02903  
Phone: (401) 222-2661  
Fax: (401) 222-2616  
TTY: (401) 222-2664  
Website: [www.richr.ri.gov](http://www.richr.ri.gov)



#### **RHODE ISLAND DEVELOPMENTAL DISABILITIES COUNCIL**

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Rhode Island Developmental Disabilities Council promotes creative ways for men, women, and children with disabilities to live more independent, fulfilling lives.

400 Bald Hill Road, Suite 515, Warwick, RI 02886

Phone: (401) 737-1238

Fax: (401) 737-3395

TTY: (401) 737-1238

Website: [www.riddc.org](http://www.riddc.org)

#### **RHODE ISLAND DISABILITY LAW CENTER**

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The Rhode Island Disability Law Center provides free legal assistance for individuals and families of children with disabilities. Services include individual representation to protect rights or secure benefits and services, self-help information, educational programs, and administrative and legal advocacy.

275 Westminster Street, Suite 401, Providence, RI 02903

Phone: (401) 831-3150

TTY: (401) 831-5335

Fax: (401) 274-5568

Website: [www.ridlc.org](http://www.ridlc.org)

#### **RHODE ISLAND PARENT INFORMATION NETWORK (RIPIN)**

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The Rhode Island Parent Information Network (RIPIN) is a statewide charitable, nonprofit organization with a collective programmatic reach that extends to every Rhode Island community and to the state's major family-serving systems, schools, associations, and agencies. RIPIN provides information, support, and training to help all Rhode Islanders become their own best advocates at school, in healthcare, and in all areas of life. RIPIN achieves family-centered, culturally competent, and community-based systems by partnering with, collaborating with, and educating key stakeholders.

RIPIN offers 11 programs and services to all families and professionals in the state, including the federally designated Parent Training and Information Center (PTIC), Parent Information Research Center (PIRC), Parents as Teachers (PAT) Program, and Parent Consultant services. RIPIN is also home to the Family Voices/Family to Family Health Information Center of Rhode Island, which offers information, education, advocacy, and peer support to families.

1210 Pontiac Avenue, Cranston, RI 02920

Phone: (401) 270-0101

Fax: (401) 270-7049

Website: [www.ripin.org](http://www.ripin.org)

#### RHODE ISLAND REGIONAL TRANSITION CENTERS

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The Rhode Island Regional Transition Centers provide information, training, and technical assistance to teachers, administrators, and families of students in special education, ages 14–21, who are preparing for the transition from school to adult life. The Centers offer a resource and curriculum library and coordinate regional training and information events through their Regional Transition Advisory Committee (TAC).

##### East Bay Collaborative

Serves: Barrington, Portsmouth, Bristol, Warren, Tiverton, Newport, East Providence,

Little Compton, Middletown

317 Market Street, Warren, RI 02885

Phone: (401) 245-2045 ext. 303

Email: [aspinwac@ride.ri.gov](mailto:aspinwac@ride.ri.gov)

#### RHODE ISLAND REGIONAL VOCATIONAL ASSESSMENT CENTERS

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These centers provide vocational assessment services for students aged 14 to 21 years who are eligible for the services of the Department of Human Services/Office of Rehabilitation Services. They assist students with their personal career goals through career counseling, vocational testing, and community work experience. Information generated from the assessment is provided to the student's Individualized Education Program (IEP) and used in establishing transition goals with the student for employment, post-secondary education and training, community participation, and independent living. Contact information is the same as that for the Rhode Island Regional Transition Centers.

##### Northern Rhode Island Collaborative

Serves: Burrillville, North Providence, Central Falls, North Smithfield, Smithfield,

Cumberland, Pawtucket, Johnston, Lincoln, Woonsocket

640 George Washington Highway, Suite 200, Lincoln, RI 02865

Phone: (401) 721-0709

Email: [jslade@nric-ri.org](mailto:jslade@nric-ri.org)

##### Providence Public Schools

Serves: Providence

434 Mt. Pleasant Avenue, Providence, RI 02908

Phone: (401) 278-0520

Email: [n.stevenin@ppsd.org](mailto:n.stevenin@ppsd.org)

**Southern Rhode Island Collaborative**

Serves: Block Island, Chariho, North Kingstown, East Greenwich, South Kingstown, Exeter,  
West Greenwich, Jamestown, Narragansett, Westerly

646 Camp Street, North Kingstown, RI 02852

Phone: (401) 295-2888

Email: [jwalejko@sorico.org](mailto:jwalejko@sorico.org)

**West Bay Collaborative**

Serves: Coventry, Warwick, Cranston, West Warwick, Foster, Glocester, Scituate

144 Bignall Street, Warwick, RI 02888

Phone: (401) 941-8353 ext. 124

Email: [curranwbc@aol.com](mailto:curranwbc@aol.com)

**RHODE ISLAND TECHNICAL ASSISTANCE PROJECT AT THE DEPARTMENT OF EDUCATION**

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The Rhode Island Technical Assistance Project offers services and support to individuals with ASDs, professionals, and families. Elements of support include personal preparation (course work at Rhode Island College), professional development opportunities, workshops and in service training, technical assistance/job embedded support to classrooms and/or individuals, a resource library and website, best practice guidelines, demonstration classrooms, and an ASD Network.

**Rhode Island College**

600 Mount Pleasant Avenue, Providence, RI 02908

Phone: (401) 456-4600

Website: [www.ritap.org](http://www.ritap.org)



**RIPTA RIDE SHARE PROGRAM**

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RIPTA provides transportation for individuals with special healthcare needs. For service, you must call 48 hours in advance.

269 Melrose Street, Providence, RI 02907

Phone: (800) 827-2127

Website: [www.ripta.com](http://www.ripta.com)

**THE SENSATIONAL CHILD, INC.**

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The Sensational Child is a non-profit organization supporting families and their children with special needs. The organization's mission is to reach out to families and their children from diagnosis through transition to adulthood.

Better public understanding and the creation of family support systems occur through parent-to-parent group meetings, playgroups, enrichment programs, educational opportunities, speaker nights, book clubs, and art instruction. Many of the groups meet in the sensory room, where both children with disabilities and their typically-developing peers can meet on an equal footing in a uniquely stimulating environment.

As a durable medical equipment provider, The Sensational Child is also a source for therapy tools and equipment, books devoted to special needs, quality developmental toys, items used in sensory integration therapy, and adaptive equipment for better organizational, daily living, and life skills.

The Sensational Child is also a training site that provides vital work experience for adults with special needs to learn valuable skills in a nurturing environment. For adults ages 18-21 years, an employment program and transition services are available.

Ultimately, the aim of The Sensational Child is to ensure a welcoming atmosphere, free from intimidation, where people can navigate the complex world of disabilities and find support by interacting with people who have been on a similar quest for the right information, the best therapy, and better understanding.

Lafayette Mill Complex, Lower Level (rear of main building)

650 Ten Rod Road, North Kingstown, RI 02852

Phone: (401) 667-2797

Fax: (401) 667-2788

Website: [www.sensationalchild.org](http://www.sensationalchild.org)

#### SIBLINK PROGRAM

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The SibLink Program at Hasbro Children's Hospital provides support to siblings of children with special healthcare needs. The program brings siblings together to share experiences so they can better cope with their feelings and with the situations that arise from their brothers' or sisters' conditions. The SibLink Program is open to all families who have children with special healthcare needs. Families are welcome no matter where their children receive their healthcare.

The Bradley Hasbro Research Center

1 Hoppin Street, Coro West Building, Suite 204, Providence, RI 02903

Phone: (401) 444-8945

Website: [www.lifespan.org/hch/services/siblink/about.htm](http://www.lifespan.org/hch/services/siblink/about.htm)

#### TECHACCESS OF RHODE ISLAND

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TechACCESS of Rhode Island is a private, non-profit resource center that serves individuals with disabilities who are interested in assistive technology. Information and referral services regarding assistive technology products, funding, and services are provided at no charge. TechACCESS also provides referrals to service providers, vendors, and advocacy services.

110 Jefferson Boulevard, Suite 1, Warwick, RI 02888

Phone: (401) 463-0202 (Voice/TTY) or (800) 916-8324

Fax: (401) 463-3433

Website: [www.techaccess-ri.org](http://www.techaccess-ri.org)

#### UNITED WAY 2-1-1 IN RHODE ISLAND

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United Way 2-1-1 provides Rhode Islanders with a call system for information 24 hours a day, 7 days a week, regarding access to resources across communities in Rhode Island. Individuals at 2-1-1 confidentially and free of charge connect callers to services and resources in their native languages.

Website: [www.211ri.org](http://www.211ri.org)

# Therapeutic Recreation

## PLAYGROUNDS

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### HASBRO BOUNDLESS PLAYGROUND

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Roger Williams Park, Providence, (401) 727-5931. Children with physical disabilities can enjoy at least 70% of the play activities at this playground without having to leave their support equipment behind. Equally important, the equipment is designed to be sensory rich and developmentally appropriate, so children with all types of abilities can laugh, play, and grow together. There is also a 3,500 square foot sensory garden that houses over 500 plants. Visitors can learn about horticulture and the natural world through plants that have different textures, scents, and colors.

### IMPOSSIBLE DREAM PLAYGROUND

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575 Centerville Road, Warwick, (401) 823-5566. Kids can be train engineers, castle dwellers, backhoe operators, and more, in addition to enjoying the variety of contraptions on which to swing, climb or ride. There's even mini-golf. The site is owned by the imPossible Dream,



a non-profit organization devoted to granting dreams to chronically ill or needy children in Rhode Island. The playground also has on-site restrooms. Open daily, 10:00 a.m. to 3:00 p.m., except holidays and holiday weekends. A \$1 donation per child is suggested; train rides cost 50 cents and are offered Monday-Friday at 11:30 a.m. and 1:30 p.m.

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#### INDIA POINT PARK

India Court, Providence. Accessible waterfront park with picnic tables, in-line skating, sledding, bike paths, and community boating.

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#### MATTY'S PLACE

Hazard School, Columbia Street, Wakefield. Designed by Kompan, Inc., the playground features modern apparatus accessible for those with special needs and a rubber-based ground cover to ensure safety. It is named in memory of five-year-old Matthew Siravo, who had epilepsy and many special needs throughout his five years of life. Matty died unexpectedly on Mother's Day in 2003.

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#### THE SARAH JANE MCCULLOUGH HANDICAPPED PLAY AREA

Richmond Elementary School, 190 Kingstown Road, Wyoming. This playground was built in memory of Sarah Jane McCullough. Sarah's family and friends wanted to create a place where children in wheelchairs could laugh, play with their siblings and friends, and create memories. Sarah passed away at the age of nine in March 2003. The playground was carefully designed to meet the needs of children and adults in wheelchairs. Featured items of play to accommodate wheelchairs are the sway fun glider, sand box, sensory activity panels, monkey bars, crazy basketball hoop, swings, seesaw, picnic tables, and curved and arch bridges. A rubberized surface offers easy accessibility for independent play. The play area is open to the public daily after school hours and on weekends.

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#### OTHER ACTIVITIES AND PROGRAMS

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##### CHALLENGED ATHLETES FOUNDATION

The Challenged Athletes Foundation helps pay for a number of different needs, including adaptive equipment and training, so that people with disabilities can get involved in organized sports or just go to summer camp. Call for details.

PO Box 910769, San Diego, CA 92191

Phone: (858) 866-0959

Fax: (858) 866-0958

Website: [www.challengedathletes.org](http://www.challengedathletes.org)

#### THE CHILDREN'S PHYSICAL DEVELOPMENTAL CLINIC

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The Children's Physical Developmental Clinic is a unique physical, motor, and recreation program that has been serving children with disabilities from Eastern Massachusetts and Rhode Island since January 1974. The program is designed to enhance perceptual-motor, gross motor, sport, aquatic, and leisure skills, as well as social development of children and youth with disabilities, ages 18 months to 18 years. Fifty-five children attend the program in two eight-week sessions during the fall semester and the spring semester each academic year. Over 100 undergraduate and graduate students from 12 academic majors serve as clinicians and group leaders in the program. The clinic is held at the John J. Kelly Gymnasium on the campus of Bridgewater State College. The clinic uses the Olympic size swimming pool, two gymnasiums, an early childhood intervention center, and a physical fitness training room.

Bridgewater State College, Kelly Gymnasium, Room 107, Bridgewater, MA 02325

Phone: (508) 531-1776

Website: [www.bridgew.edu/cpdc](http://www.bridgew.edu/cpdc)

#### FIRST SWING RHODE ISLAND

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First Swing Rhode Island conducts golf clinics for people with disabilities and instructional clinics for therapists. Participants with disabilities work with trained rehabilitation, PGA, and recreational professionals under the expertise of First Swing Rhode Island instructors to learn how to swing golf clubs using adaptive golf carts for seated individuals and/or adaptive golf clubs and equipment.

Phone: (877) 444-3774

Website: [www.firstswingri.org](http://www.firstswingri.org)

#### GREENLOCK THERAPEUTIC RIDING CENTER

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The Greenlock Therapeutic Riding Center offers hippotherapy for children with disabilities, including autism, and horseback riding for people of all ages with physical, developmental, or emotional disabilities. It is a place where 130 riders, with all types of disabilities, come six days a week to sit on the Greenlock horses to strengthen their legs, teach their bodies to balance, or learn to hold their heads up by themselves. A horse serves as a bridge to a world that may, until now, have been inaccessible. Each session is geared to the individual and can be flexible, depending on the rider's needs. Sessions are conducted by certified riding instructors and the hippotherapy component by licensed physical, occupational, and speech therapists. The Greenlock Riding Center accepts Medical Assistance and other forms of insurance.

55 Summer Street, Rehoboth, MA 02769

Phone: (508) 252-5814

Website: [www.greenlock.org](http://www.greenlock.org)



#### LEND A HAND THERAPEUTIC RIDING FOUNDATION

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The Lend A Hand Therapeutic Riding Foundation is located in Cranston, RI, and is one of Rhode Island's leading therapeutic riding facilities. The riding programs at Lend A Hand are designed to meet the needs of children and/or adults with physical, mental, or social disabilities, as well as those who are eager to learn about horse riding in a therapeutic environment. Our programs focus on disabilities such as autism, cerebral palsy, behavioral problems, developmental disabilities, speech impairments, muscular dystrophy, muscle weakness, sensory integration disorders, learning disabilities, attention deficit disorders, and more. Each child or adult is carefully evaluated by a professionally-trained staff of licensed therapists.

151 Laten Knight Road, Cranston, RI 02921

Phone: (401) 826-9278

#### RHODE ISLAND FAMILY GUIDE—SUMMER CAMP DIRECTORY

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The Rhode Island Family Guide is published three times a year and is free to all families. Each resource guide contains comprehensive information on the following topics: entertainment, healthcare, education, camps, and alternative methods to good health.

PO Box 163, Warren, RI 02885

Phone: (401) 247-0850

Fax: (401) 247-0850

Website: [www.rifamilyguide.com](http://www.rifamilyguide.com)

#### SAIL TO PREVAIL

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Sail to Prevail provides mainstream, complimentary, and recreational therapeutic services (including an adaptive sailing program) that develop independent living skills for individuals who have experienced spinal cord injury and related nervous system disorders.

PO Box 1264, Newport, RI 02840

Phone: (401) 849-8898

Fax: (401) 848-8898

Website: [www.sailtoprevail.org](http://www.sailtoprevail.org)

#### **SPECIAL OLYMPICS**

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Special Olympics offers year-round training and competition in Olympic-type sports for children and adults with mental retardation and/or closely-related developmental disabilities. Unified Sports teams up athletes with and without cognitive disabilities for bowling, basketball, soccer, softball, volleyball, sailing, and golf. The Motor Activities Training Program provides comprehensive motor activity and recreation training for people with significant developmental disabilities. Athletic Leadership programs are "off the field" initiatives that involve athletes at all levels. These include the Officials Programs for Athletes, the Sargent Shriver Global Messengers Program, and Athletes Congresses.

33 College Hill Road, Building 31, Warwick, RI 02886

Phone: (401) 823-7411

Fax: (401) 823-7415

Website: [www.specialolympicsri.org](http://www.specialolympicsri.org)

#### **VSA ARTS OF RHODE ISLAND**

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VSA Arts of Rhode Island is a statewide non-profit organization providing high quality programs and opportunities for people with disabilities to actively participate in the visual, literary, and performing arts.

500 Prospect Street, Pawtucket, RI 02860

Phone: (401) 725-0247

TTY: (800) 745-5555

Fax: (401) 725-0397

Website: [www.vsartsri.org](http://www.vsartsri.org)

# Other Educational Settings

Note: See Section 5 of this guide for more information on Other Educational Settings.

## COVENTRY

### **The Groden School**

2 Saint Vincent de Paul Street

Coventry, RI 02816

Serves: ages 12-21 years old

Phone: (401) 615-2600

Fax: (401) 615-2408

## CRANSTON

### **Cornerstone School**

665 Dyer Avenue

Cranston, RI 02920

Serves: ages 18 months-21 years old

Phone: (401) 942-2388

Fax: (401) 944-7480

## EAST PROVIDENCE

### **Bradley Hospital Center for Autism and Developmental Disabilities (CADD)**

#### **Day Program**

1011 Veterans Memorial Parkway

East Providence, RI 02915

Serves: grades K-12

Phone: (401) 432-1000

Fax: (401) 432-1500

### **Bradley School**

1011 Veterans Memorial Parkway

East Providence, RI 02915

Serves: grades K-12

Phone: (401) 432-1411

Fax: (401) 432-1224

### **The Wolf School**

215 Ferris Avenue

East Providence, RI 02916

Serves: grades 2-8

Phone: (401) 432-9940

## GLOCESTER

### **Harmony Hill School, Inc.**

63 Harmony Hill Road

Chepachet, RI 02814

Serves: males only

Phone: (401) 949-0690

Fax: (401) 949-4419

## LINCOLN

### **The Spurwink School**

365 River Road

Lincoln, RI 02865

Serves: grades K-12

Phone: (401) 781-4380

Fax: (401) 334-3783

## MIDDLETOWN

### **Looking Upwards, Inc.**

438 East Main Road

Middletown, RI 02842

Serves: adults with developmental  
disabilities (day program)

Phone: (401) 847-0960

Fax: (401) 849-0290

NARRAGANSETT

**Ocean Tides, Inc.**

635 Ocean Road

Narragansett, RI 02882

Serves: grades 7-12

Phone: (401) 789-1016

Fax: (401) 788-0924

NEWPORT

**James L. Maher School**

120 Hillside Avenue

Newport, RI 02840

Serves: grades K-12

Phone: (401) 846-3518

Fax: (401) 847-9459

NORTH PROVIDENCE

**St. Mary's Home for Children**

**George N. Hunt Campus School**

440 Fruit Hill Avenue

North Providence, RI 02911

Serves: grades 1-12

Phone: (401) 353-3900 ext. 311

Fax: (401) 353-0984

PAWTUCKET

**The Tides School**

242 Dexter Street

Pawtucket, RI 02860

Serves: grades 7-12

Phone: (401) 742-8060

Fax: (401) 724-8899

Fax: (401) 722-1815

PORTSMOUTH

**The Bradley School**

2820 East Main Road

Portsmouth, RI 02871

Serves: grades K-12

Phone: (401) 682-1816

Fax: (401) 682-1823

PROVIDENCE

**Center for Individualized Training and Education (CITE)**

15 Bough Street

Providence, RI 02909

Serves: children Pre K-age 21

Phone: (401) 351-0610

Fax: (401) 351-5510

**Elmwood Community School**

801 Elmwood Avenue

Providence, RI 02907

Serves: grades 7-12

Phone:(401) 490-4095

Fax: (401) 490-4096

**The Groden Center**

86 Mount Hope Avenue

Providence, RI 02906

Serves: grades Pre K-12

Phone: (401) 274-6310

Fax: (401) 421-3280

**Mount Pleasant Academy**

1246 Chalkstone Avenue

Providence, RI 02908

Serves: grades Pre K-8

Phone: (401) 521-4335

Fax: (401) 521-3282

**Ocean Tides School**

260 Highland Avenue  
 Providence, RI 02906  
 Serves: grades 9-12  
 Phone: (401) 861-3778  
 Fax: (401) 831-0309

**The Providence Center School**

520 Hope Street  
 Providence, RI 02906  
 Serves: grades Pre K-12  
 Phone: (401) 276-4531  
 Fax: (401) 276-4015

**School One**

220 University Avenue  
 Providence, RI 02906  
 Serves: grades 9-12  
 Phone: (401) 331-2497  
 Fax: (401) 421-8869

**The Tides School**

790 Broad Street  
 Providence, RI 02905  
 Serves: grades 9-12  
 Phone: (401) 467-8228  
 Fax: (401) 467-8899

## SAUNDERSTOWN

**Kingston Hill Academy**

850 Stony Fort Road  
 Saunderstown, RI 02874  
 Serves: grades K-5  
 Phone: (401) 783-8282  
 Fax: (401) 783-5656

## SOUTH KINGSTOWN

**Bradley School**

4781 Tower Hill Road  
 Wakefield, RI 02879  
 Serves: grades Pre K-12  
 Phone: (401) 284-1040  
 Fax: (401) 284-1045

## WARWICK

**Eleanor Briggs School**

116 Long Street  
 Warwick, RI 02886  
 Serves: grades 2-12, males only  
 Phone: (401) 732-1540  
 Fax: (401) 732-4658

**Pathways Strategic Teaching Center**

3445 Post Road  
 Warwick, RI 02886  
 Serves: grades Pre K-6  
 Phone: (401) 739-2700 ext. 275  
 Fax: (401) 737-8907

**Sargent Rehabilitation Center**

800 Quaker Lane  
 Warwick, RI 02818  
 Serves: ages 3-21 years old  
 Phone: (401) 886-6603  
 Fax: (401) 886-6632

**Shawomet Alternative School**

1642 West Shore Road  
 Warwick, RI 02889  
 Serves: grades 6-8  
 Phone: (401) 732-3722  
 Fax: (401) 732-3723

WEST WARWICK

**The Tides School**

222 Washington Street

West Warwick, RI 02893

Serves: grades 7-12

Phone: (401) 826-3788

Fax: (401) 823-4694

WESTERLY

**Frank Olean Center**

93 Airport Road

Westerly, RI 02891

Serves: ages 15+ (day program)

Phone: (401) 315-0143

Fax: (401) 596-3945

WOONSOCKET

**Action Based Enterprises**

115 Ricard Street

Woonsocket, RI 02895

Serves: grades K-8

Phone: (401) 767-5959

Fax: (401) 767-5957

**Hillside Alternative Program**

115 Ricard Street

Woonsocket, RI 02895

Serves: grades 9-12

Phone: (401) 762-0769

Fax: (401) 762-0958

**Viola M. Berard School**

PO Box 1700

Woonsocket, RI 02895

Serves: grades K-12

Phone: (401) 235-7410

Fax: (401) 767-9107

# State Agencies

## RHODE ISLAND DEPARTMENT OF BEHAVIORAL HEALTHCARE, DEVELOPMENTAL DISABILITIES, AND HOSPITALS

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The mission of the Rhode Island Department of Behavioral Healthcare, Developmental Disabilities, and Hospitals (BHDDH) is to assure access to quality services and supports for Rhode Islanders with developmental disabilities, mental health and substance abuse issues, and chronic long-term medical and psychiatric conditions. In addition, BHDDH provides planning services for the development of new services and prevention activities. The divisions within BHDDH include Behavioral Healthcare Services (mental health centers and substance abuse prevention, education, and treatment programs), Developmental Disabilities (residential services, day/employment services, and family supports), Eleanor Slater Hospital, and licensing for community providers.

### Divisions of Behavioral Healthcare Services

Barry Hall, 14 Harrington Road, Cranston, RI 02920

Phone: (401) 462-2339

Fax: (401) 462-3604

Website: [www.bhddh.ri.gov](http://www.bhddh.ri.gov)

### Division of Developmental Disabilities

Barry Hall, 14 Harrington Road, Cranston, RI 02920

Phone: (401) 462-3234

Fax: (401) 462-6189

Website: [www.bhddh.ri.gov](http://www.bhddh.ri.gov)

## RHODE ISLAND DEPARTMENT OF CHILDREN, YOUTH, AND FAMILIES

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The Rhode Island Department of Children, Youth, and Families (DCYF) is responsible for promoting and protecting the health, well-being, and development of children and their families. The four major divisions of the agency include child welfare, children's behavioral health, juvenile corrections, and licensing (for child care, foster care, and adoption) services. Through multiple programs extending through a range of community-based care to residential treatment, DCYF provides child protection, child welfare, children's behavioral health and education, preventive services to children at risk of abuse/neglect, support services for children and families in need, and services for youth requiring community supervision or incarceration.

101 Friendship Street, Providence, RI 02903

Phone: (401) 528-3502

Website: [www.dcyf.ri.gov](http://www.dcyf.ri.gov)

#### RHODE ISLAND DEPARTMENT OF EDUCATION

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The Rhode Island Department of Education (RIDE) oversees public education programs in Rhode Island for children ages 3-21, including the provision of appropriate services to advance the education of children with special needs.

The Office of Special Populations within RIDE monitors a number of services that are administered by the individual school districts. Special Education programs operate in all school districts, including charter public schools, to provide individually-designed instruction to meet the unique needs of each child with a disability. RIDE also regularly monitors a school district's compliance with state and federal regulations related to the education of children with disabilities and offers mediation and due process hearings in cases of disagreement.

255 Westminster Street, Providence, RI 02903

Phone: (401) 222-3505

Website: [www.ride.ri.gov](http://www.ride.ri.gov)

#### RHODE ISLAND DEPARTMENT OF HEALTH

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The Rhode Island Department of Health (HEALTH)'s primary mission is to prevent disease and to protect and promote the health and safety of the people of Rhode Island. As Rhode Island has no local health departments, all programs and services are coordinated by the agency Divisions and Centers, which include Community, Family Health, and Equity, Emergency Preparedness and Response, Environmental and Health Services Regulation, Health Data and Analysis, Health Information Technology, Health Laboratories, Infectious Disease and Epidemiology, Management Services, Medical Examiners, Public Health Communications, and Vital Records.

The Office of Special Health Care Needs (OSHCN) located in the Division of Community, Family Health, and Equity ensures family-centered, community based, integrated systems of services for children and youth with special healthcare needs (CYSHCN) through infrastructure building activities, training/technical assistance, and collaboration with families, other state agencies, health plans, and community agencies. As the Title V CYSHCN designated agency, the OSHCN provides direct support and contract management to pediatric specialty services, specific disability groups, interdepartmental projects, and parent support organizations.

3 Capitol Hill, Providence, RI 02908

Phone: HEALTH Information Line (401) 222-5960

RI Relay: 711

Website: [www.health.ri.gov](http://www.health.ri.gov)



#### **RHODE ISLAND DEPARTMENT OF HUMAN SERVICES**

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The Rhode Island Department of Human Services (DHS) administers programs and services for children (including children with special healthcare needs), families, and adults. The Center for Child and Family Health oversees the CEDARR, Home-Based Therapeutic Services (HBTS), Kids Connect, Personal Assistance Services and Supports (PASS), Respite, and Early Intervention (EI) programs. DHS also administers the Rhode Island Medical Assistance Program (Medicaid), including Fee-for-Service Medicaid, Katie Beckett, RIteCare, and RIteShare. Additionally, DHS supports low-income families through programs like Childcare Assistance, Head Start, Rhode Island Works (formerly FIP), SNAP (Supplemental Nutrition Assistance Program, formerly Food Stamps), and Early Head Start.

Center for Child and Family Health

Hazard Building, Ground Level, 74 West Road, Building #74, Cranston, RI 02920

Phone: (401) 462-5300

Website: [www.dhs.ri.gov](http://www.dhs.ri.gov)

#### **GOVERNOR'S COMMISSION ON DISABILITIES**

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The Governor's Commission on Disabilities ensures that all people with disabilities have the opportunity to exercise their rights and responsibilities as Rhode Island citizens and can reach their maximum potential for independence, human development, productivity, and self-sufficiency. The Commission is responsible for ensuring state agencies comply with state and federal disability rights laws. The Commission also acts as a mediator for disability discrimination complaints.

John O. Pastore Center

41 Cherry Dale Court, Cranston, RI 02920

Phone: (401) 462-0101

Fax: (401) 462-0106

Website: [www.disabilities.ri.gov](http://www.disabilities.ri.gov)

# The Cracked Pot

***The following story, “The Cracked Pot,” is by an unknown author and shares the message that all children are a special gift.***

A water bearer in India had two large water pots. They hung on opposite ends of a pole, which he carried across his neck. One of the pots had a crack in it and while the other pot was perfect and always delivered a full portion of water at the end of the long walk from the stream to the master’s house, the cracked pot always arrived only half full.

For a full two years this went on daily, with the water bearer delivering only one and a half pots full of water in his master’s house. Of course, the perfect pot was proud of its accomplishments, perfect to the end for which it was made. But the poor cracked pot was ashamed of its imperfection, miserable that it could accomplish only half of what it had been made to do.

After two years of what it perceived to be a bitter failure, it spoke to the water bearer one day by the stream. “I am ashamed of myself and I want to apologize to you.”

“Why?” asked the water bearer. “What are you ashamed of?”

“I have been able, for these past two years, to deliver only half my load because this crack in my side causes water to leak out all the way back to your master’s house. Because of my flaws, you have to do all of this work and you don’t get full value from your efforts,” the pot said.

The water bearer felt sorry for the old cracked pot and in his compassion he said, “As we return to the master’s house, I want you to notice the beautiful flowers along the path.”

Indeed, as they went up the hill, the cracked pot took notice of the sun warming beautiful flowers on the side of the path and this cheered it. But at the end of the trail, it still felt bad because it had leaked out half its load, and so again it apologized to the water bearer for its failure.

The water bearer said to the pot, “Did you notice that there were flowers only on your side of the path, but not on the other pot’s side? That’s because I have always known about your flaw and I took advantage of it. I planted flower seeds on your side of the path and everyday while we have walked back from the stream, you’ve watered them. For two years I have been able to pick these beautiful flowers to decorate my master’s table. Without you being just the way you are, he would not have this beauty to grace his house.”

*MORAL: Each of us has our own unique flaws. We’re all cracked pots. But it’s the cracks and flaws we each have that make our lives together so very interesting and rewarding. We need to take each person for what they are and look for the good in them. There is a lot of good out there. Every day we look in the mirror we can wonder what flowers we’ll unknowingly be watering that day.*

# Websites

## THE AMERICAN ACADEMY OF PEDIATRICS

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“A report by the American Academy of Pediatrics: The Pediatrician’s Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children.”

<http://aappolicy.aappublications.org>

## ASPERGER SYNDROME COALITION OF THE UNITED STATES

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A national non-profit organization committed to providing the most up-to-date and comprehensive information on Asperger Disorder and related conditions. The coalition is based in Washington, D.C.

<http://aspergersyndrome.org>

## ASPERGER SYNDROME TEENS

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A website started by a teen with Asperger who is willing to help other teens who have Asperger Syndrome.

[www.aspergerteens.com](http://www.aspergerteens.com)

## ASPERGER’S ASSOCIATION OF NEW ENGLAND

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Provides families with information on local support groups for children and adults.

[www.aane.org](http://www.aane.org)

## AUTISM: HAND IN HAND

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An educational website with a collection of programs, learning materials, play activity ideas, and more.

[www.autismhandinhand.com](http://www.autismhandinhand.com)

## AUTISM NETWORK INTERNATIONAL

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An autistic-run self-help and advocacy group for autistic people.

<http://ani.autistics.org>

## AUTISM—PDD RESOURCES NETWORK

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Topics range from research to diagnosis, education (including lists of schools K–12 by state and information on college preparation and the application procedure), job search, and estate planning.

[www.autism-pdd.net](http://www.autism-pdd.net)

#### THE AUTISM PROJECT

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The Autism Project is a unique collaboration of families and professionals whose mission is to create a comprehensive system of services to support individuals with ASDs, their families, and the professionals who support and educate them. With support from the Rhode Island Department of Health and funds from the Department of Health and Human Services, the Autism Project offers a Family Training and Support Center for families of children with ASDs. The website is updated with training and social group schedules and has additional resources for families and professionals.

[www.theautismproject.org](http://www.theautismproject.org)

#### AUTISM RESEARCH INSTITUTE

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Primarily devoted to conducting research and to sharing the results of research on the causes of autism and the methods of preventing, diagnosing, and treating autism and other severe behavioral disorders of childhood. The Institute provides research-based information to families and professionals throughout the world.

[www.autism.com](http://www.autism.com)

#### AUTISM SOCIETY OF AMERICA

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One of the leading organizations in the United States for promoting awareness and developing support for the autism community. The Society was founded in 1965 by a small group of families working on a volunteer basis out of their homes, and it has over 20,000 members with nearly 200 chapters.

[www.autism-society.org](http://www.autism-society.org)

#### AUTISM SPEAKS

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Autism Speaks is a non-profit organization dedicated to funding global biomedical research into the causes, prevention, treatments, and cures for autism; to raising public awareness about autism and its effects on individuals, families, and society; and to bringing hope to all who deal with the hardships of this disorder. Autism Speaks aims to bring the autism community together as one strong voice to urge the government and private sector to listen to our concerns and take action to address this urgent global health crisis.

[www.autismspeaks.org](http://www.autismspeaks.org)

#### **AUTISM TEACHING TOOLS**

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Offers practical information about teaching a child who has autism. It contains an index of over 200 books, songs, games, and toys that can assist educators and families in teaching their children. The goal is to have a source of materials for families to refer to when teaching specific cognitive concepts or skills. The website welcomes comments from families and professionals who have developed effective ways to teach a particular skill or concept.

[www.autismteachingtools.com](http://www.autismteachingtools.com)

#### **AUTISTICS.ORG**

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Links autistic people with the services needed to lead productive lives. The goal of the website is to create a global database of information and resources for persons on the autistic spectrum.

[www.autistics.org](http://www.autistics.org)

#### **CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)**

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The CDC is one of several agencies that have projects in place to study autism spectrum disorders.

[www.cdc.gov/ncbddd/autism](http://www.cdc.gov/ncbddd/autism)

#### **CLINICALTRIALS.GOV**

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The government provides patients, family members, healthcare professionals, and members of the public with easy access to information on clinical trials for a wide range of diseases and conditions. This site currently contains approximately 7,600 clinical studies sponsored by the National Institutes of Health, other federal agencies, and the pharmaceutical industry in over 89,000 locations worldwide. Studies listed in the database are conducted primarily in the United States and Canada but include locations in about 80 countries. ClinicalTrials.gov receives over three million page views per month and hosts approximately 11,000 visitors daily.

<http://clinicaltrials.gov/ct2>

#### **DEFEAT AUTISM NOW!**

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A project of The Autism Research Institute dedicated to the exploration, evaluation, and dissemination of scientifically documented biomedical interventions for individuals within the autism spectrum, through the collaborative efforts of clinicians, researchers, and families.

[www.defeatautismnow.com](http://www.defeatautismnow.com)

#### THE DOUG FLUTIE, JR. FOUNDATION

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The Foundation's mission is to aid financially-disadvantaged families that need assistance in caring for their children with autism, to fund education and research into the causes and consequences of childhood autism, and to serve as a clearinghouse and communications center for new programs and services developed for people with autism.

[www.dougflutiejrfoundation.org](http://www.dougflutiejrfoundation.org)

#### FAMILY VILLAGE

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A global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide them with services.

[www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

#### THE GRODEN CENTER, INC.

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The Groden Center, Inc., the largest provider in Rhode Island of services dedicated to individuals with ASD, was founded in 1976 with a mission to support, teach, nurture, and challenge individuals with ASD to reach their greatest level of independence, productivity, and participation in their communities. A variety of programs accomplish this goal by providing the most effective educational and therapeutic services, by advancing knowledge and best practices through research, education, and training, and by involving, educating, and supporting families in caring for and advocating for their children.

[www.grodencenter.org](http://www.grodencenter.org)

#### NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

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Promotes health, wellness, and quality of life in those with disabilities. Great information on autism spectrum disorders.

[www.cdc.gov/ncbddd/autism](http://www.cdc.gov/ncbddd/autism)

#### NATIONAL DISSEMINATION CENTER FOR CHILDREN WITH DISABILITIES

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Serves as a central source of information on the Individuals with Disabilities Education Act (IDEA), the nation's special education law; No Child Left Behind, as it relates to children with disabilities; and on effective educational practices. Includes a state resource list for each state, giving helpful contacts and information on parent training. Can be contacted by telephone, email, or mail, in English or Spanish.

[www.nichcy.org](http://www.nichcy.org)

**NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT**

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A public service website covering many autism-related topics.

[www.nichd.nih.gov/autism](http://www.nichd.nih.gov/autism)

**NATIONAL INSTITUTE OF MENTAL HEALTH**

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The Institute's scientists are dedicated to understanding the workings and interrelationships of the various regions of the brain and to developing preventative measures and new treatments for autism.

[www.nimh.nih.gov/publicat/autism.cfm](http://www.nimh.nih.gov/publicat/autism.cfm)

**NETWORK OF INTERNATIONAL FARM COMMUNITIES**

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A tremendous organization that promotes efforts "to provide farmstead communities which meet the residential, vocational, and recreational needs of the growing population of adults with autism." The organization was founded in 1974 and has member communities all over the world. The website offers links to many of these organizations, historical and statistical information, and links to other resources.

[www.autismnet.net](http://www.autismnet.net)

**NEW ENGLAND CENTER FOR CHILDREN**

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Since its founding in 1975, The New England Center for Children has remained true to its original mission: providing state-of-the-art education and individualized treatment, care, and respect for children with autism and other disabilities.

[www.necc.org](http://www.necc.org)

**ONLINE ASPERGER SYNDROME INFORMATION AND SUPPORT**

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Run by families.

[www.aspergersyndrome.org](http://www.aspergersyndrome.org)

**UNITED STATES FOOD AND DRUG ADMINISTRATION**

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Information on medications approved by the Food and Drug Administration.

[www.fda.gov](http://www.fda.gov)

**WRIGHTSLAW.COM**

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Families, educators, and attorneys come to Wrightslaw for accurate, up-to-date information about special education law and advocacy for children with disabilities.

[www.wrightslaw.com](http://www.wrightslaw.com)



#### YALE AUTISM PROGRAM

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The Autism Program at Yale University is an interdisciplinary group of clinicians and scholars dedicated to providing comprehensive clinical services to children with autism spectrum disorders and their families. It is also one of the leading research centers in the world and was recently recognized as a National Institutes of Health Autism Center of Excellence. The program involves infants, toddlers, preschool, and school-age children, as well as young adults (18-21 years) with autism and related disorders. It integrates highly experienced professionals from the fields of clinical psychology, neuropsychology and neuroimaging, child psychiatry, speech-language pathology, social work, genetics, and the biological sciences, as well as psychopharmacology and psychiatric nursing. The clinical and research activities are located in the Child Study Center at Yale University School of Medicine in New Haven, Connecticut.

<http://childstudycenter.yale.edu/autism>

#### YALE DEVELOPMENTAL DISABILITIES CLINIC

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Offers comprehensive, multidisciplinary evaluations for children with social disabilities, usually focusing on the issues of diagnosis and intervention. The clinic is located in the Child Study Center at Yale University School of Medicine in New Haven, Connecticut.

<http://childstudycenter.yale.edu/autism/clinic.aspx>

## Spanish Links

#### INTERNATIONAL AND NATIONAL AUTISM LINKS

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[www.autism-resources.com/links/organizations.html](http://www.autism-resources.com/links/organizations.html)

[www.manitasporautismo.com](http://www.manitasporautismo.com)

# Christopher and Jonathan's Story

***The following story, written by Amy, a mother of two children with ASD, describes the importance of providing her sons with treatment and services. Amy is convinced that her children's success is due to all of her wonderful supports.***

My second son Jonathan was the perfect baby. He was happy, smiling all the time...a pure joy to our entire family. He even slept for 5 hours straight his first night home from the hospital! Our first son, Christopher, on the other hand, had always been more difficult from the day he was born. He truly didn't seem ready to face the world outside the womb. He cried all the time, didn't nurse well and pretty much never slept. What we didn't know then was the thing these two very different little people had in common was autism.

My two children, so very different, have both been diagnosed with autism. My first child was older when we discovered it, just past three. As new parents, we panned off all his behaviors and sensitivities to his personality. "He's just over sensitive. He just can't handle new situations, noise, crowds, etc." Even our pediatrician backed us up saying, he was fine. That is until his third year check up. At this time the pediatrician bluntly exclaimed, "Maybe he has autism." We were flabbergasted and shocked, to say the least. And then, after we picked ourselves off the floor, the autism journey began with doctors, diagnosis, therapists, the public school system's Special Ed department, etc.

I'm pleased to say my oldest is doing very well. He's a happy, funny little seven-year old. He still has many sensitivities and issues, but he has a lot of great strengths too, like his amazing imagination and great sense of humor. I truly believe he will survive in this world and maybe some day move off this vast spectrum of autism and just be an adult who's a bit on the quirky side.

The jury is still out on my second child, Jonathan. The language and skills that he had as a 15 month old slowly disappeared. Now, at age four he seems to be finally climbing back up and making some progress with the help of picture exchange and a lot services from his wonderful teachers and therapists.

We knew Jonathan had a problem early on and he received extensive services, but his journey seems a bit tougher to me. Maybe it's just harder for us to see a child so sweet have to struggle so much just to communicate with the people who love him. Still, I have hope for him as well.

All I know is that we can't give up on these little guys or stop trying to figure out how this happens. I do believe services and interventions are key to helping them. And, I'm so glad we have the services and therapies to work with them to communicate and be happier children. The one thing I do know is that I love my kids, and the diagnosis of autism will not change that!

# Frequent Family Questions

## QUESTIONS ANSWERED BELOW:

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### GENERAL:

- » How common are Autism Spectrum Disorders (ASDs)?
- » Is Asperger Disorder a form of an ASD?
- » What is the difference between Autism and PDD or PDD-NOS?
- » What are the characteristics that define a diagnosis of PDD or an ASD?
- » Are there common concerns or early signs noted by families that eventually lead to an ASD diagnosis?
- » At what age can an ASD be diagnosed?

### OBTAINING A DIAGNOSIS:

- » If my child is really delayed in some way, how will I know? Can't we just wait and see if he or she grows out of it?
- » My child can talk, but his teacher still thinks he or she has an ASD. How can I be sure?
- » My child is three and not talking yet. Does this mean he or she has an ASD?
- » How can my child be assessed if he or she cannot talk?

### AFTER DIAGNOSIS:

- » What is the prognosis for my child with an ASD?
- » What about medication for my child with an ASD?
- » When should teachers begin to offer vocational instruction?
- » Can a student with an ASD be included in the general education setting?

## GENERAL

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### HOW COMMON ARE AUTISM SPECTRUM DISORDERS?

It is estimated that 1 in 110 children born in the US today have an Autism Spectrum Disorder (ASD) or some form of pervasive developmental disorder. Its prevalence makes ASD one of the most common developmental disabilities. ASDs are more common in boys than girls.

### IS ASPERGER DISORDER A FORM OF AN ASD?

Yes. Asperger Disorder is an ASD that affects the way a person communicates and relates to others. People with Asperger Disorder generally have language skills, are “high functioning,” and are of average or above average intelligence. Concrete and literal thinking and an obsession—or extremely narrow interest—often characterize this disorder. Children with Asperger Disorder may not receive a diagnosis immediately, since they frequently develop speech at an average rate.

### WHAT IS THE DIFFERENCE BETWEEN AUTISM AND PDD OR PDD-NOS?

The Pervasive Developmental Disorders are a group of disorders including Classic Autism, Childhood Disintegrative Disorder, Rett’s Syndrome, Pervasive Development Disorder (PPD), Pervasive Development Disorder—Not Otherwise Specified (PPD-NOS), Asperger Disorder. They are also known as ASDs. A person’s diagnosis is determined based upon evaluation of criteria such as which areas are impacted and how strongly the area is impacted. PDD-NOS is an atypical ASD.

### WHAT ARE THE CHARACTERISTICS THAT DEFINE A DIAGNOSIS OF AN ASD?

The characteristics required for a diagnosis of any ASD are listed in the American Psychological Association’s *Diagnostic and Statistical Manual of Mental Disorders*. The three major characteristics are problems in communication or use of verbal language, poor social skills, and a restricted range of interests and repetitive behaviors.

**ARE THERE COMMON CONCERNS OR EARLY SIGNS NOTED BY FAMILIES THAT EVENTUALLY LEAD TO AN ASD DIAGNOSIS?**

There are common concerns expressed by families and pediatricians prior to the diagnosis of an ASD. Some of them include, but are not limited to:

1. Child lacks speech and/or had words and lost them.
2. Child speaks extremely well for a three year old, but can't play or imitate and has tantrums.
3. Child appears to be deaf and does not answer when called or react to loud noises.
4. Child does not make eye contact with parent/caregiver.
5. Child does not comment about or notice surroundings.
6. Child has unusual, odd behaviors, including severe tantrums and self-injurious behavior, is difficult to control, engages in self-stimulatory behaviors (e.g., flapping, rocking, spinning), and has no concept of danger.
7. Child ignores or does not play with other children.

**AT WHAT AGE CAN AN ASD BE DIAGNOSED?**

Children are now being evaluated and diagnosed at an earlier age, many as early as 16 months of age.

**OBTAINING A DIAGNOSIS**

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**IF MY CHILD IS REALLY DELAYED IN SOME WAY, HOW WILL I KNOW? CAN'T WE JUST WAIT AND SEE IF HE OR SHE GROWS OUT OF IT?**

First, trust your instincts and tell your concerns to your doctor. Your doctor can assess if your child is reaching the appropriate developmental milestones and, if needed, refer your child for further evaluation. Families can also access the Early Intervention Program for an assessment if they have any concerns regarding their children's development. Early Intervention services are available in every state for children ages birth to three years old.

It's important for families not to take a "wait and see" approach regarding their children's development. Research shows that early intervention is key to improving developmental delays—including ASDs. A good resource for early signs is the campaign "Learn the Signs. Act Early." developed by the US Centers for Disease Control and Prevention (CDC). For more information, visit the CDC website at [www.cdc.gov/actearly](http://www.cdc.gov/actearly)

MY CHILD CAN TALK, BUT HIS TEACHER STILL THINKS HE OR SHE HAS AN ASD.

HOW CAN I BE SURE?

Many children and adults with ASDs do talk! To know for sure if your child has an ASD, find a developmental pediatrician, psychiatrist, or psychologist specializing in children. Only these professionals are clinically trained to diagnose any form of an ASD.

MY CHILD IS THREE AND NOT TALKING YET. DOES THIS MEAN HE OR SHE HAS AN ASD?

No! There are many different reasons to explain why a three year old isn't talking. The first step to an answer is to discuss your concerns with your pediatrician. Consider getting your child's hearing and vision tested to rule out these as a factor in his or her delay. After a pediatrician does a screening, you will have important information to use in deciding if your child needs further evaluation from a developmental pediatrician or other professional.

HOW CAN MY CHILD BE ASSESSED IF HE OR SHE CANNOT TALK?

Language is only one area of an evaluation. Within that part of the evaluation, the clinician looks at a child's ability to communicate. This includes a wide range of non-verbal skills and developmental milestones. This is why it's important to have an evaluation completed by a licensed team of professionals with experience working with and evaluating individuals with ASDs.

## AFTER DIAGNOSIS

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WHAT IS THE PROGNOSIS FOR MY CHILD WITH AN ASD?

It is impossible to make a generalization about how any individual child will grow and progress. All children continue to develop, despite delays. What we do know is how early the intervention begins and the quality of programming are key factors to a child's improved development. Today, a child diagnosed with an ASD will receive different interventions beginning at an earlier age than was possible many years ago. This means each child's chances for improving communication and life skills are greater today than years ago.

WHAT ABOUT MEDICATION FOR MY CHILD WITH AN ASD?

There is no medication specifically prescribed for individuals with diagnoses of ASDs. That said, there are medications that can be prescribed to treat related symptoms and co-existing conditions.

#### WHEN SHOULD TEACHERS BEGIN TO OFFER VOCATIONAL INSTRUCTION?

With the families' permission, teachers should introduce basic vocational skills in elementary school, and then slowly build on these skills throughout middle school and high school. According to the Autism Society of America, teachers should help their students with ASDs to develop vocational and community living skills at the earliest age possible. These skills help children develop independence and become participating members of their communities, and they provide the opportunity for students to make more choices about their daily lives.

#### CAN A STUDENT WITH AN ASD BE INCLUDED IN THE GENERAL EDUCATION SETTING?

Absolutely! It is important to work with your team at school to determine when, where, and for how long your child will be included in the regular education setting. Researchers are currently studying the impact of inclusive settings on students with ASDs, and most educators agree that students with ASDs can benefit from regular interaction with their peers.

The challenge for educators is to identify appropriate methods of providing individualized education programs to children with disabilities in regular education classrooms. "Those involved with children with autism must be concerned that the enthusiasm for integrated placements not take precedence over the more important goal of appropriate education" (Koegel and Koegel, 1996). This means that each child needs to be continually assessed to evaluate whether the inclusion setting is appropriate and the child continues to be an active participant and learner in the setting. Sitting to the side with an aide doing separate, non-adapted work is not a good inclusion model.



# Important Laws Affecting Individuals with Disabilities

Several laws, amendments, and regulations are designed to protect the rights of people with disabilities in education, work, and daily life in the community. The laws vary in their scope and implementation. A brief description of the laws is listed below, along with web links to access the actual legislation.

In 2009, Rhode Island convened a twenty-three member special joint legislative commission to make a comprehensive study of the education of children with ASDs. The commission will focus on the diagnosis, assessment, and prevalence of children with ASDs in the state, the effect and role of families, appropriate goals for education, effective interventions and educational programs, and public policy approaches to ensuring access to appropriate education and personnel preparation.

## SECTION 504 OF THE REHABILITATION ACT OF 1973

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This law was the first federal civil rights law to protect people with disabilities. Its language is very similar to other civil rights legislation applying to discrimination on the basis of sex or race. The Law “establishes a mandate to end discrimination and to bring handicapped persons into the mainstream of American life.” It provides: “No otherwise qualified handicapped person shall, on the basis of handicap, be excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination under any program or activity, which receives or benefits from Federal financial assistance.”

Not only does Section 504 prohibit discrimination in work and accommodation, it provides protection to disabled people in education. Qualifying children are entitled to a free and public education under Section 504 and are protected from discrimination or retaliation in the educational setting. Likewise, Section 504 protects disabled individuals from discrimination in public higher education institutions.



The Statute, 29 U.S.C. Section 794, can be found at [www.animallaw.info/statutes/stusfd29usc794.htm](http://www.animallaw.info/statutes/stusfd29usc794.htm)

The Final Regulations, 34 C.F.R. Section 104, can be found at [www.ed.gov/policy/rights/reg/ocr/edlite-34cfr104.html](http://www.ed.gov/policy/rights/reg/ocr/edlite-34cfr104.html)

## AMERICANS WITH DISABILITIES ACT

The Americans with Disabilities Act (ADA) was signed into law in 1990. The ADA is similar to Section 504 of the Rehabilitation Act of 1973 and extends civil rights protection to persons with disabilities in private sector employment, public services, public accommodation, transportation, and telecommunications. Under ADA, a person with a disability is one who: 1) has a mental or physical impairment that substantially limits that person in a major life activity; 2) has a record of such an impairment; and 3) is regarded as having such an impairment. Though the law was enacted in 1990, not all parts went into effect at the same time; specific requirements are still being clarified.

The Federal Regulations, 35 C.F.R. 35-101 et seq., can be found at [www.ed.gov/policy/rights/reg/ocr/edlite-28cfr35.html](http://www.ed.gov/policy/rights/reg/ocr/edlite-28cfr35.html)

## INDIVIDUALS WITH DISABILITIES EDUCATION ACT

The Individuals with Disabilities Education Act (IDEA) provides that states, through local public school systems, must provide all eligible disabled students with a free and appropriate public education in the least restrictive environment possible from the time they are three years old until the end of their 21st year. The IDEA also requires services for infants and toddlers with disabilities.

The law was first enacted in 1970 and substantially revised in 1997 and again in 2004. The IDEA provides significant procedural and substantive rights to disabled children and their families and serves as the primary source of guidance on the education of disabled students. Under the IDEA, a child is guaranteed the right to participate in the regular education environment unless, after the full use of supplementary aids and services, he or she is unable to make meaningful progress. The IDEA requires that an Individualized Education Program (IEP) be developed for each eligible disabled child for use as a blueprint for the child's program each year. In addition, numerous provisions secure the family's rights to meaningfully participate in all aspects of decision-making for their child's program. IDEA, 20 U.S.C. Section 1400 et seq., and the Federal regulations, 34 C.F.R. Section 300 et seq., can be found at IDEA Practices, a website maintained by the Council for Exceptional Children and the US Department of Education at [www.cec.sped.org/contnet/NavigationMenu/PolicyAdvocacy/IDEAresources](http://www.cec.sped.org/contnet/NavigationMenu/PolicyAdvocacy/IDEAresources)

## INDIVIDUALS WITH DISABILITIES EDUCATION IMPROVEMENT ACT OF 2004

On December 3, 2004, President Bush signed Public Law 108-446, the Individuals with Disabilities Education Improvement Act (IDEA 2004).

This law affects 6.7 million children with disabilities in public schools across the US. The new law is very similar to the No Child Left Behind Act and requires accountability for all students regardless of their abilities. A summary of some of the most critical changes in IDEA 2004 that affect children with disabilities and their families can be found at [www.nationalparentcenters.org/idea/letter.htm](http://www.nationalparentcenters.org/idea/letter.htm). The complete bill can be downloaded from [www.copaa.org/pdf/houserep.pdf](http://www.copaa.org/pdf/houserep.pdf)

## WORK INCENTIVES IMPROVEMENT ACT OF 1999

An important piece of legislation passed Congress in 1999, designed to remove legislative barriers and to provide legislative incentives for people with disabilities to work. The goals of this bill, called the Work Incentives Improvement Act of 1999 (Section 331), include amending the Social Security Act to expand the availability of healthcare coverage for working individuals with disabilities and establishing Ticket to Work and Self-Sufficiency programs in the Social Security Administration to provide meaningful work opportunities to people with disabilities. Section 331:

- » Expands state options under Medical Assistance for workers with disabilities.
- » Continues Medical Assistance coverage for working individuals with disabilities.
- » Establishes grants to develop and implement state infrastructures to support working individuals with disabilities.
- » Demonstrates coverage of workers with potentially severe disabilities.
- » Establishes a Ticket To Work and Self-Sufficiency Program.
- » Prohibits the use of work activity as a basis for review of an individual's disabled status.
- » Establishes state grants for work incentives assistance to disabled beneficiaries.
- » Establishes a demonstration project providing for reductions in disability insurance benefits base earnings.
- » Expedites eligibility determinations for applications of former long-term beneficiaries who have completed an extended period of eligibility.

The Act may be found at [http://disability.law.uiowa.edu/csadp\\_docs/ssdi\\_ssi.txt](http://disability.law.uiowa.edu/csadp_docs/ssdi_ssi.txt)

# Diagnostic Criteria

Many families are curious how physicians diagnose their children with Autism Spectrum Disorders (ASDs). The following are the actual diagnostic criteria that doctors and other professionals use when evaluating children on the Spectrum. The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V) is due to be released in May 2013.

Please note that the numbers to the left of the diagnosis are the DSM-IV codes that are used by professionals and insurance companies to identify the disorder that a child may have.

## 299.00 AUTISTIC DISORDER

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### DIAGNOSTIC CRITERIA

- A. A total of six or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
- (1) Qualitative impairment in social interaction, as manifested by at least two of the following:
    - (a) Marked impairment in the use of multiple nonverbal behaviors such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction.
    - (b) Failure to develop peer relationships appropriate to developmental level.
    - (c) Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (for example, lack of showing, bringing, or pointing to objects of interest).
    - (d) Lack of social or emotional reciprocity.
  - (2) Qualitative impairments in communication as manifested by at least one of the following:
    - (a) Delay in or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
    - (b) In individuals with speech, marked impairment in the ability to initiate or sustain a conversation with others.
    - (c) Stereotyped and repetitive use of language or idiosyncratic language.
    - (d) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

- (3) Restricted repetitive and stereotyped patterns of behavior, interest, and activities, as manifested by at least one of the following:
  - (a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
  - (b) Apparently inflexible adherence to specific, nonfunctional routine or rituals.
  - (c) Stereotyped and repetitive motor mannerisms (for example, hand or finger flapping or twisting).
  - (d) Persistent preoccupation with parts of objects.
- B. Delays or abnormal functioning in at least one of the following areas: with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

## 299.80 ASPERGER DISORDER

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### DIAGNOSTIC CRITERIA

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
  - (1) Marked impairment in the use of multiple nonverbal behaviors such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction.
  - (2) Failure to develop peer relationships appropriate to developmental level.
  - (3) A lack of spontaneous seeking to share enjoyment, interests or achievements with other people (for example, a lack of showing, bringing, or pointing out objects of interest to other people).
  - (4) Lack of social or emotional reciprocity.
- B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  - (1) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
  - (2) Apparently inflexible adherence to specific, nonfunctional routines or rituals.
  - (3) Stereotyped and repetitive motor mannerisms (for example, hand or finger flapping or twisting).
  - (4) Persistent preoccupation with parts of objects.
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant general delay in language (for example, single words used by age 2 years, communicative phrases used by age 3 years).

- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate, self-help skills, adaptive behavior, and curiosity about the environment in childhood.

#### 299.80 PERVASIVE DEVELOPMENTAL DISORDER– NOT OTHERWISE SPECIFIED (PDD-NOS)

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##### DIAGNOSTIC CRITERIA

- A. PDD-NOS is a form of “atypical autism” where a child may present with symptoms that do not fit the criteria for Autistic Disorder because of the late age of onset and/or atypical symptoms.
- B. PDD-NOS should be used when there is a severe and pervasive impairment in development of reciprocal social interaction or verbal and nonverbal communication skills, or when the atypical symptoms identified in social relationships, social communication, and imaginative play or thought are present.

#### 299.10 CHILDHOOD DISINTEGRATIVE DISORDER

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##### DIAGNOSTIC CRITERIA

- A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.
- B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
  - (1) Expressive or receptive language.
  - (2) Social skills or adaptive behavior.
  - (3) Bowel or bladder control.
  - (4) Play.
  - (5) Motor skills.
- C. Abnormalities of functioning in at least two of the following areas:
  - (1) Qualitative impairment in social interaction (for example, impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity).
  - (2) Qualitative impairments in communication (for example, delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play).
  - (3) Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypes and mannerisms.

## 299.80 RETT SYNDROME

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### DIAGNOSTIC CRITERIA

#### A. All of the following:

- (1) Apparently normal prenatal (before birth) and perinatal (after birth) development.
- (2) Apparently normal psychomotor development through the first 5 months after birth.
- (3) Normal head circumference at birth.

#### B. Onset of all of the following after the period of normal development:

- (1) Deceleration of head growth between ages 5 and 48 months.
- (2) Loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (for example, hand-wringing or hand washing).
- (3) Loss of social engagement early in the course (although often social interaction develops later).
- (4) Appearance of poorly coordinated gait or trunk movements.
- (5) Severely impaired expressive and receptive language development with severe psychomotor retardation.

# Glossary

## **504 PLAN**

An education plan developed for a student who does not meet the eligibility for special education services but requires modifications to his or her educational program to promote school success.

## **ADVOCATE**

One who defends, vindicates, or espouses any cause by argument; to speak, plead, or argue in favor of.

## **ALLERGY**

A condition in which the body has an exaggerated response to a substance (e.g., food or drug).

## **ANGELMAN SYNDROME**

A diagnosis confirmed by a specific genetic test, characterized by hand flapping, little or no speech, attention deficits, hyperactivity, and delays in motor development.

## **ANXIETY DISORDERS**

Disorders often characterized by an intense apprehension or fear and distress that can be accompanied by anxiety episodes that can occur in various settings.

## **APRAXIA**

A speech condition where individuals have difficulty with oral motor planning.

## **ATTENTION DEFICIT DISORDER (ADD)**

A neurological disorder characterized by impulsivity and short attention span.

## **ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)**

A neurological disorder characterized by impulsivity, short attention span, and hyperactivity.

## **ATYPICAL**

An aspect of behavior that is not representative of what is thought of as in the range of normative or usual for individuals.

## **AUDIOLOGIST**

A licensed professional who assesses and treats hearing impairments.

**BIPOLAR DISORDER**

A disorder that is marked by extreme changes in mood, thought, energy, and behavior. This disorder is also known as Manic Depression.

**CHROMOSOME**

Components in a cell, occurring in pairs—one from the mother, the other from the father—that contain genetic information.

**COMMUNICATION**

A process by which information is exchanged between two or more individuals through a common system of words, symbols, signs, or behaviors.

**CUE**

An action on the part of one person that indicates to the other that they should begin a specific action.

**DEFICIT**

Difficulties in intellectual skills, language abilities, social skills, adaptive abilities, and other skills that can be developmental or may reflect a loss of abilities.

**DETERIORATION**

A worsening of deficits or impairments over time.

**DEVELOPMENTAL DELAYS**

The lack of development by a certain age of basic skills such as walking, talking, etc.

**DEVELOPMENTAL MILESTONES**

A set of functional skills or age-specific tasks that most children can do at a certain age range.

**DEVELOPMENTAL/BEHAVIORAL PEDIATRICIAN**

A doctor specializing in the care of children and specifically trained to focus on development and behavior.

**DIAGNOSIS**

The process of identifying a disease or condition by its signs, symptoms, and the results of various diagnostic procedures.

**DNA**

The molecule in the nucleus of a cell that contains genetic information that determines the structure, function, and behavior of the cell.



#### **EARLY INTERVENTION**

A program that provides services to eligible children with developmental delays from birth to three years of age. Services include complete developmental testing, in-home support, diagnosis, and links to community services and resources.

#### **EPILEPSY**

A chronic disorder characterized by recurrent unprovoked seizures.

#### **FAMILY RESOURCE SPECIALIST**

A person who has personal experience and can assist families with system navigation and provide them with resources, support, and connections to other families.

#### **FRAGILE X SYNDROME**

The most common cause of genetically-inherited mental impairment. Fragile X can range from subtle learning disabilities to severe intellectual challenges.

#### **GASTROENTEROLOGIST**

A doctor that specializes in digestive disease and disorders.

#### **GENETIC**

A term relating to genes or inherited characteristics.

#### **GENETIC DISORDER**

A condition that is passed from one family member to the next.

#### **GENETICIST**

A doctor who specializes in conditions that are passed from one family member to the next.

#### **GESTURE**

A movement of the body or a part of the body used to communicate with others (i.e., to express an idea or emotion).

#### **GLUTEN FREE/CASEIN FREE (GF/CF) DIET**

Casein is found in dairy products, and gluten is found in wheat, oats, and rye. The GF/CF Diet removes all products that contain gluten and casein from the diet to monitor any resulting positive changes in behavior.

#### **HORMONE**

A chemical substance secreted into body fluids and transported to another organ that produces a specific effect, such as altering metabolism or modifying the functioning of the organ.

**HYPERACTIVE**

A state or tendency to be overly active or excitable.

**HYPERLEXIA**

A syndrome observed in children who have an amazing ability to read words, numbers, or letters, but usually with limited comprehension.

**INDIVIDUALIZED EDUCATION PROGRAM (IEP)**

A written plan developed and agreed upon by the student's parent(s)/caregiver(s) and the school system to identify services that the school system is required to provide to accommodate the child's needs.

**INDIVIDUALIZED FAMILY SERVICE PLAN (IFSP)**

A written plan for services developed by an Early Intervention team based on the result of an evaluation or assessment and the concerns of the family.

**INTELLECTUAL DISABILITY**

Significant delays in intellectual skills and adaptive functioning as evaluated by the use of IQ tests and assessments of individuals' independent and self-help skills.

**LEARNING DISABILITY**

Any condition that interferes with an individual's ability to learn, thought to be caused by difficulties in processing and integrating information.

**MANNERISM**

An idiosyncrasy of behavior that is specific to or distinctive of an individual.

**MENTAL RETARDATION (MR)**

Significant delays in intellectual skills and adaptive functioning as evaluated by the use of IQ tests and assessments of individuals' independent and self-help skills.

**MOTOR CONTROL**

The ability to regulate and direct purposeful movements of the body, including fine motor control of the hands and fingers as well as gross motor control of large movements and posture.

**NATURAL ENVIRONMENTS**

The day-to-day settings, routines, and activities in which young children learn best.

**NEUROLOGICAL CONDITION**

A condition that relates to the nervous system's structure, functions, and abnormalities.

**NEUROLOGIST**

A medical doctor who specializes in the diagnosis and treatment of disorders of the nervous system.

**NEWBORN SCREENING**

A screening at birth for specific metabolic conditions, provided at all birthing hospitals in Rhode Island under the administration of the Rhode Island Department of Health.

**NONVERBAL LEARNING DISORDER (NLD)**

A disorder that is neurological in origin and affects a child's ability to organize visual and spatial information, adapt to new social settings, and/or accurately read nonverbal cues.

**OBSESSIVE COMPULSIVE DISORDER (OCD)**

An anxiety disorder characterized by intense, unwanted thoughts and rituals that are beyond an individual's control, such as hand washing, hoarding, etc.

**OCCUPATIONAL THERAPIST**

A licensed professional who provides evaluation and therapy related to meaningful activities of daily life, such as self-care skills, education, work, or social interaction.

**OPPOSITIONAL DEFIANT DISORDER (ODD)**

A psychiatric disorder characterized by two different sets of problems, one of which includes aggressiveness and the other a tendency to purposefully bother and irritate others.

**PEER RESOURCE SPECIALIST**

Parents or family members of children with special healthcare needs who have experience/knowledge about resources, supports, and services and provide the unique family perspective necessary to promote family-centered services.

**PHYSICAL THERAPIST**

A licensed professional who provides evaluation and therapy using physical and mechanical means, such as massage, regulated exercise, water, light, heat, and electricity.

**PRADER-WILLI SYNDROME**

A syndrome diagnosed by a genetic test and often associated with impulsive eating, a compact body build, underdeveloped sexual characteristics, and poor muscle tone. Other characteristics can include delays in speech, motor control difficulties, feeding problems in infancy, sleep disturbances, skin picking, temper tantrums, and a high pain threshold.

**PROCEDURAL SAFEGUARDS**

Rights specified by state and federal laws for families of children in Early Intervention to encourage families to play an active role in the decision-making process of their children's education.

**PROMPT**

A verbal or physical support that helps a child get through an action.

**PSYCHIATRIC DISORDER**

A mental, emotional, or behavioral disorder.

**PSYCHIATRIST**

A medical doctor who specializes in the diagnosis and treatment of mental disorders.

**PSYCHOLOGIST**

A non-medical doctor with a Doctor of Philosophy (Ph.D.) or a Doctor of Psychology (Psy.D.) who specializes in the diagnosis and treatment of mental and emotional problems.

**PSYCHOPHARMACOLOGIC TREATMENTS**

Medications used to treat psychiatric conditions.

**REHABILITATION**

The restoration of or improvement in an individual's ability to perform functions such as activities of daily living.

**SECRETIN**

A hormone produced by the small intestines to help the body in the digestive process.

**SEIZURE DISORDER**

A condition that causes seizures, which involve an involuntary body movement of the limbs, head, or neck.

**SELF-STIMULATION OR "STIMMING"**

An individual's fixation on an object or part of the body.

**SEMANTIC-PRAGMATIC DISORDER**

A disorder characterized by delayed language development problems. Symptoms include learning to talk by memorization, repeating phrases out of context, difficulty following conversations, and difficulty understanding questions.

**SENSORIMOTOR**

Describes a function in both sensory and motor aspects of bodily activity.

**SERVICE COORDINATOR**

An individual assigned to each family in Early Intervention to provide a single point of contact for the family to obtain services identified in the written Individualized Family Service Plan and to provide assistance as needed.

**SPECIAL EDUCATION**

Educational services required by law for students with disabilities, 3-21 years of age, to ensure the provision of a free and appropriate education designed to meet each child's unique needs.

**STIMMING OR SELF-STIMULATION**

An individual's fixation on an object or part of the body.

**TOURETTE'S SYNDROME**

A neurological disorder characterized by linguistic and physical tics.

**TRANSITION**

Passage from one form, state, style, or place to another.

**WILLIAMS SYNDROME**

A rare disorder, caused by an abnormality in chromosomes, that occurs at random, can affect brain development in varying degrees, and cause some physical effects and problems.

# Abbreviations and Acronyms

**AANE**

Asperger's Association of New England

**AARC**

Autism Asperger's Resource Center

**ABA**

Applied Behavioral Analysis

**ABC**

Autism Behavior Checklist

**AD**

Autistic Disorder

**ADD**

Attention Deficit Disorder

**ADHD**

Attention Deficit Hyperactivity Disorder

**ADI-R**

Autism Diagnostic Interview-Revised

**ADOS**

Autism Diagnostic Observation Schedule

**AIT**

Auditory Integration Therapy

**ANI**

Autism Network International

**APD**

Auditory Processing Disorder

**ARI**

Autism Research Institute

**AS**

Asperger Syndrome

**ASA**

Autism Society of America

**ASD**

Autism Spectrum Disorder

**BD**

Behavior Disorder

**CAN**

Cure Autism Now

**CARS**

Childhood Autism Rating Scale

**CDC**

Centers for Disease Control and Prevention

**CEDARR**

Comprehensive Evaluation, Diagnosis, Assessment, Referral, and Re-evaluation

**CHAT**

Checklist for Autism in Toddlers

**CPR**

Cardiac Pulmonary Resuscitation

<b>CSA</b> Center for the Study of Autism	<b>ESY</b> Extended School Year
<b>CYSHCN</b> Children and Youth with Special Health Care Needs	<b>FAPE</b> Free Appropriate Public Education
<b>DAN</b> Defeat Autism Now	<b>FAQ</b> Frequently Asked Questions
<b>DD</b> Developmental Disability	<b>FBA</b> Functional Behavioral Assessment
<b>DHS</b> Department of Human Services	<b>FEAT</b> Families for Effective Autism Treatment
<b>DPT</b> Diagnostic Prescriptive Teacher	<b>FOP</b> Family Outreach Program
<b>DSM</b> Diagnostic Statistical Manual	<b>FV</b> Family Voices of Rhode Island
<b>DSM-IV</b> Diagnostic Statistical Manual, fourth edition	<b>FXS</b> Fragile X Syndrome
<b>DTT</b> Discrete Trail Training	<b>GARS</b> Gilliam Autism Rating Scale
<b>DX</b> Diagnosis	<b>GFCF</b> Gluten Free/Casein Free
<b>EEG</b> Electro Encephalo Gram	<b>HBTS</b> Home-Based Therapeutic Services
<b>EI</b> Early Intervention	<b>HEALTH</b> Department of Health
<b>ELL</b> English Language Learner	<b>HFA</b> High Functioning Autism
<b>ESL</b> English as a Second language	<b>HIPPY</b> Home Instruction Program for Preschool Youngsters

**IBT**  
Intensive Behavioral Training

**ICD**  
International Classification of Diseases

**ID**  
Intellectual Disability

**IDEA 2004**  
Individuals with Disabilities Education Improvement Act

**IEP**  
Individualized Education Program

**IFSP**  
Individualized Family Service Plan

**LD**  
Learning Disabled

**LFA**  
Low Functioning Autism

**M-CHAT**  
Modified Checklist for Autism in Toddlers

**MDT**  
Multi-Disciplinary Team

**MR**  
Mental Retardation

**NACD**  
National Academy of Child Development

**NHPRI**  
Neighborhood Health Plan of Rhode Island

**NICHCY**  
National Information Center for Children and Youth with Disabilities

**NIH**  
National Institutes of Health

**NLD**  
Nonverbal Learning Disorder

**NT**  
Neurologically Typical

**NVLD**  
Nonverbal Learning Disability

**OASIS**  
Online Asperger Syndrome Information and Support

**OCD**  
Obsessive Compulsive Disorder

**ODD**  
Oppositional Defiant Disorder

**ORS**  
Office of Rehabilitation Services

**OSCIL**  
Ocean State Center for Independent Living

**OT**  
Occupational Therapy

**PAHI**  
Peer Assisted Health Initiative

**PARI**  
PARI Independent Living Center

**PASS**  
Personal Assistance Services and Supports



**PAT**

Parents as Teachers

**PDD**

Pervasive Developmental Disorder

**PDD-NOS**

Pervasive Developmental Disorder–Not  
Otherwise Specified

**PECS**

Picture Exchange Communication Systems

**PPEP**

Pediatric Practice Enhancement Project

**PSN**

Parent Support Network

**PT**

Physical Therapy

**RIARC**

Rhode Island Association for Retarded Citizens

**RIPIN**

Rhode Island Parent Information Network

**SCERTS**

Social Communication, Emotional Regulation,  
and Transactional Supports

**SLP**

Speech and Language Pathology

**SI**

Sensory Integration

**SSDI**

Social Security Disability Insurance

**SSI**

Supplemental Security Income

**TEACCH**

Treatment and Education of Autistic  
and Communication Related Handicapped  
Children

**TQP**

Team of Qualified Professionals

**TS**

Tourette's Syndrome

**VNA**

Visiting Nurse Association

**VR**

Vocational Rehabilitation

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