

PHOTOGRAPH
OF CHILD

Complete Care Notebook

This Complete Care Notebook Belongs To:

CHILD'S NAME

DATE OF BIRTH

TIME OF BIRTH

HOSPITAL WHERE CHILD WAS BORN

ADDRESS

CITY

STATE

How to Use Your Complete Care Notebook

WHAT IS A COMPLETE CARE NOTEBOOK?

Being the parent of a child with special health care needs can feel overwhelming at times. Your child may need care and services, on a regular basis, from many different types of providers. This *Complete Care Notebook* was designed to help you keep track of and organize important information about your child's health and healthcare.

WHAT DOES THE COMPLETE CARE NOTEBOOK CONTAIN?

- » Forms for recording emergency medical information about your child.
- » Forms for recording your family's health history.
- » Forms for tracking your child's health.
- » A *Family Voices Resource Guide* that provides contact information on statewide agencies that assist families of children with special needs.
- » A glossary that defines healthcare terms and medical specialties.
- » A pocket folder to store important forms to take to medical visits.
- » A CD that you can use to print extra copies of *Complete Care Notebook* forms.
- » A clear zipper pocket to save receipts, bills, business cards, etc.

HOW CAN THE COMPLETE CARE NOTEBOOK HELP ME?

In caring for your child with special health care needs, you may get information and paperwork from many sources. This *Notebook* will help you organize the most important information about caring for your child in a central place. The *Complete Care Notebook* makes it easier for you to find and share key information with others who are part of your child's care team.

Use your *Complete Care Notebook* to:

- » Store emergency information about your child and family.
- » File information about your child's health care history.
- » List telephone numbers for health care providers and community organizations.
- » Track changes in your child's medicines, treatments, and health conditions(s).
- » Keep track of medical appointments and conversations with healthcare providers.
- » Share new information about your child's care with doctors, school or daycare staff, and others caring for your child.
- » Track expenses related to your child's care.

WHAT ARE SOME HELPFUL HINTS FOR USING MY CHILD'S COMPLETE CARE NOTEBOOK?

- » Store the *Complete Care Notebook* where it is easy to find.
- » Add new information to the *Complete Care Notebook* whenever there is a change in your child's diagnoses, treatment, and development.
- » Consider taking the *Complete Care Notebook* with you to appointments and hospital visits so that information you need will be close at hand.
- » Rather than carrying the entire *Notebook* to your child's appointments, you may choose to use the folder located in the back of the binder to carry individual pages of the *Notebook*.

HOW DO I SET UP MY CHILD'S COMPLETE CARE NOTEBOOK?

1. Gather information you already have about your child's health.
 - » This may include reports from recent doctor's visits, a recent summary of a hospital stay, names and phone numbers of physicians, hospitals, and relatives, this year's school plan, test results, or informational pamphlets.
2. Decide which information about your child is most important to keep in the *Notebook* and file it in the appropriate section.
 - » Which of these sections could help you keep track of information about your child's health care?
 - » What information do you look up often?
 - » What information do others need for your child?
 - » How can you organize the *Complete Care Notebook* so it will be the most helpful to you?
3. Update the *Complete Care Notebook* regularly.
 - » Identify which forms require updating.
 - » Add information to the *Notebook* as it becomes available. For example, if you receive new information from health care providers, update the appropriate *Notebook* pages. Keep track of your child's condition(s) on a regular basis. Log phone conversations with providers, and track expenses related to your child's care.
 - » Extra copies of tracking forms can be printed from the CD found in the clear CD holder in the front of the *Notebook*.
 - » Store receipts, bills, business cards, etc in the clear zipper pocket.

Emergency Information

*“Don’t find fault.
Find a remedy.”
Henry Ford*

This section provides forms with important information on your child’s health for medical providers in case of an emergency, including identification information, family contact information, and medical insurance.

This section is the most important part of the *Complete Care Notebook* to keep updated.

Below is a table describing the information you should record in each of the forms in this section.



Form	Use this form to record...
CHILD’S EMERGENCY MEDICAL INFORMATION	Important medical information needed for health providers in an emergency. Please note that this form should be updated often.
FAMILY’S INFORMATION	Contact information for your family, your child’s primary caregivers, and other emergency contacts.
MEDICAL INSURANCE	Medical insurance and policy information needed for emergency care providers.

Emergency Information

CHILD'S DATE OF BIRTH

CHILD'S FIRST NAME

MIDDLE

LAST

NICKNAME

SOCIAL SECURITY #

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

CELL PHONE ()

BLOOD TYPE

CHILD'S CONDITION(S)

ALLERGIES

HOSPITAL REGISTERED FREQUENT FLYER

YES

NO

IF YES, NAME OF HOSPITAL

ETHNICITY

RELIGION

CUSTOMS THAT MAY AFFECT MEDICAL TREATMENT OR HEALTH CARE

PREFERRED LANGUAGE (WAY OF COMMUNICATING, SIGN, USE OF EQUIPMENT, TTY, COMMUNICATION BOARD, ETC.)

Technology Dependence

SPECIAL TECHNOLOGY NEEDS (TUBES, CATHETERS, PORTS, ETC.)

PRECAUTIONS TO TAKE WHILE DEALING WITH TECHNOLOGY

DO NOT RESUSCITATE

PARENT/GUARDIAN SIGNATURE

DATE

DO RESUSCITATE

PARENT/GUARDIAN SIGNATURE

DATE

Primary Care Provider

NAME

ADDRESS

CITY

STATE

ZIP CODE

PHONE NUMBER

PREFERRED HOSPITAL

Current Medications

MEDICATION

DATE STARTED

DOSAGE

INSTRUCTIONS (INCLUDE TIME GIVEN)

Last Medical Emergency

DATE

REASON

NAME OF HOSPITAL

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

Emergency Contacts

NAME

RELATIONSHIP

PHONE ()

CELL PHONE ()

NAME

RELATIONSHIP

PHONE ()

CELL PHONE ()

NAME

RELATIONSHIP

PHONE ()

CELL PHONE ()

Family's Information		
MOTHER'S NAME		
SOCIAL SECURITY #		
ADDRESS		
CITY	STATE	ZIP CODE
HOME ()	WORK ()	
CELL ()	FAX ()	
E-MAIL		
FATHER'S NAME		
SOCIAL SECURITY #		
ADDRESS		
CITY	STATE	ZIP CODE
HOME ()	WORK ()	
CELL ()	FAX ()	
E-MAIL		
PRIMARY CAREGIVER, IF DIFFERENT FROM ABOVE (FOR EXAMPLE; GRANDPARENT, AUNT, OTHER LEGAL GUARDIAN)		
NAME		SOCIAL SECURITY #
ADDRESS		
CITY	STATE	ZIP CODE
HOME ()	WORK ()	
CELL ()	FAX ()	
E-MAIL		
OTHERS TO BE CALLED IN CASE OF AN EMERGENCY (CLERGY, OTHER RELATIVES AND FRIENDS)		
NAME		SOCIAL SECURITY #
ADDRESS		
CITY	STATE	ZIP CODE
HOME ()	WORK ()	
CELL ()	FAX ()	
E-MAIL		
NAME		SOCIAL SECURITY #
ADDRESS		
CITY	STATE	ZIP CODE
HOME ()	WORK ()	
CELL ()	FAX ()	
E-MAIL		

Primary Insurance

INSURANCE COMPANY

INSURANCE NUMBER

GROUP #

DEDUCTIBLE

POLICY HOLDER

EMPLOYER'S NAME

EMPLOYER'S ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

Secondary Insurance

INSURANCE COMPANY

INSURANCE NUMBER

GROUP #

DEDUCTIBLE

POLICY HOLDER

EMPLOYER'S NAME

EMPLOYER'S ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

Other Insurance or Health Plan

INSURANCE COMPANY

INSURANCE NUMBER

GROUP #

DEDUCTIBLE

POLICY HOLDER

EMPLOYER'S NAME

EMPLOYER'S ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

*“Being a parent is a noble job.
Never underestimate the power you have
to help create a better future not only for
your children, but for everyone.”*

Anonymous

Health History



This section provides forms to record your family’s medical history and track changes in your child’s medical diagnosis and development. It is important to update this section if your child’s diagnosis and/or eating habits change.

Below is a table describing the information you should record in each of the forms in this section.

Form	Use this form to record...
MOTHER’S PREGNANCY HISTORY	Medications taken, problems, illnesses that occurred during the mother’s pregnancy.
CHILD’S BIRTH HISTORY	Date, name of hospital, and health conditions present on the day of your child’s birth.
FAMILY MEDICAL HISTORY	Illnesses or health conditions of the child’s mother, father, siblings, or other relatives.
CHILD’S DIAGNOSIS	Your child’s diagnosis, the date diagnosed, and the doctor who made the diagnosis.
CHILD’S FEEDING HISTORY	Changes in the type of food your child eats or the way he or she eats.
CHILD’S DEVELOPMENT HISTORY	The dates when your child develops important skills, such as smiling, walking, speaking, and playing.

Mother's Pregnancy History

HOW MANY MONTHS PREGNANT WERE YOU WHEN YOU FIRST SAW A DOCTOR?

HOW MANY TIMES DID YOU SEE THE DOCTOR DURING YOUR PREGNANCY?

DOCTOR/OBSTETRICIAN

PRACTICE/CLINIC NAME

ADDRESS

TELEPHONE ()

DRUGS AND MEDICATIONS TAKEN BY MOTHER BEFORE AND DURING PREGNANCY:

BEFORE PREGNANCY	HOW LONG?	DURING PREGNANCY	HOW LONG?

MOTHER'S ILLNESSES DURING PREGNANCY:

DID YOU HAVE ANY PROBLEMS WITH THIS PREGNANCY OR WITH OTHER PREGNANCIES IN THE PAST?

ARE THERE ANY OTHER COMMENTS ABOUT YOUR PREGNANCY THAT YOU THINK ARE IMPORTANT?

Child's Birth History

CHILD'S NAME

DATE OF BIRTH

BIRTH WEIGHT

LENGTH

WAS BABY FULL TERM (9 MONTHS)? YES NO IF NO, HOW MANY WEEKS EARLY WAS THE BABY BORN?

LENGTH OF LABOR

TYPE OF DELIVERY: NORMAL BREECH PRECIPITATE CAESAREAN

CHILD'S CONDITION AT BIRTH

CHILD'S PROBLEMS FOLLOWING BIRTH

DID MOTHER HAVE PROBLEMS WITH OTHER PREGNANCIES?

NAME OF HOSPITAL WHERE CHILD WAS BORN

ADDRESS

TELEPHONE ()

HOW MANY DAYS DID YOUR CHILD STAY IN THE HOSPITAL AFTER BIRTH? TO DATE DATE

NAME OF CHILD'S PRIMARY DOCTOR IN THIS HOSPITAL

SPECIALTY TELEPHONE ()

ADDRESS

CHILD'S APGAR SCORES: 1 MINUTE 5 MINUTES

NAME OF HOSPITAL CHILD WAS TRANSFERRED TO

ADDRESS TELEPHONE ()

REASON FOR TRANSFER

CHILD WAS IN THIS HOSPITAL FROM TO DATE DATE

NAME OF CHILD'S PRIMARY DOCTOR IN THIS HOSPITAL

SPECIALTY TELEPHONE ()

ADDRESS

Child's Diagnosis	
DIAGNOSIS	
ABBREVIATION	ALSO CALLED
DOCTOR(S) WHO DIAGNOSED	
SPECIALTY OF DOCTOR(S)	DATE(S) DIAGNOSED
DIAGNOSIS	
ABBREVIATION	ALSO CALLED
DOCTOR(S) WHO DIAGNOSED	
SPECIALTY OF DOCTOR(S)	DATE(S) DIAGNOSED
DIAGNOSIS	
ABBREVIATION	ALSO CALLED
DOCTOR(S) WHO DIAGNOSED	
SPECIALTY OF DOCTOR(S)	DATE(S) DIAGNOSED
DIAGNOSIS	
ABBREVIATION	ALSO CALLED
DOCTOR(S) WHO DIAGNOSED	
SPECIALTY OF DOCTOR(S)	DATE(S) DIAGNOSED
DIAGNOSIS	
ABBREVIATION	ALSO CALLED
DOCTOR(S) WHO DIAGNOSED	
SPECIALTY OF DOCTOR(S)	DATE(S) DIAGNOSED
DIAGNOSIS	
ABBREVIATION	ALSO CALLED
DOCTOR(S) WHO DIAGNOSED	
SPECIALTY OF DOCTOR(S)	DATE(S) DIAGNOSED
DIAGNOSIS	
ABBREVIATION	ALSO CALLED
DOCTOR(S) WHO DIAGNOSED	
SPECIALTY OF DOCTOR(S)	DATE(S) DIAGNOSED
WEBSITES RELATED TO CHILD'S DIAGNOSIS	

Child's Feeding History

Sometimes children must have changes made to their diets. These changes may be either the type of food they eat or the way they eat it. Keeping track of these changes is important. If your child should ever have a problem with feeding, your doctor will want to know about your child's feeding history.

WHEN YOUR BABY CAME HOME FROM THE HOSPITAL, WHAT TYPE OF FOOD DID HE/SHE EAT?

- BREAST MILK
- REGULAR FORMULA (SPECIFY WHAT BRAND, COLOR OF CAN)
- SPECIAL FORMULA (SPECIFY WHAT BRAND, COLOR OF CAN)
- HOMEMADE (LIST INGREDIENTS)

IF YOUR BABY'S FEEDING HABITS CHANGED, WHAT WAS THE CHANGE AND WHY?

BREAST TO BOTTLE CHILD'S AGE

WHY?

FORMULA CHANGE CHILD'S AGE

WHAT WAS THE CHANGE?

WHY?

BOTTLE TO CUP CHILD'S AGE

WHY?

STARTED SOLID FOOD CHILD'S AGE

WHY?

OTHER CHANGES (FOR EXAMPLE; TUBE FEEDING)

CHANGE CHILD'S AGE

WHY?

CHANGE CHILD'S AGE

WHY?

CHANGE CHILD'S AGE

WHY?

CHANGE CHILD'S AGE

WHY?

FEEDING HISTORY

FAVORITE FOODS

FOODS YOUR CHILD REFUSES TO EAT

FOOD ALLERGIES

HOW MUCH DOES HE/SHE EAT?

HOW LONG DOES IT TAKE YOUR CHILD TO TAKE A BOTTLE OR EAT A MEAL?

DOES YOUR CHILD HAVE ANY PROBLEMS WITH FOOD, SUCH AS SPITTING UP, VOMITING, DIARRHEA, REFUSING TO EAT, ETC.?

IS FEEDING DIFFICULT DURING MEALTIME?

TIP: THREE OR FOUR TIMES A YEAR, YOU MAY WANT TO RECORD IN THIS BOOK THE FOODS YOUR CHILD

LIKES AND DISLIKES SO YOU CAN HAVE A RECORD OF ANY CHANGE IN FOOD PREFERENCES.

Child's Development History

The term “development” refers to an increase in skill and function, such as your child’s ability to move, talk, and take care of himself or herself. Because children with special health care needs may develop at a rate different from other children, it is important to keep a record of your child’s skill development.

IMPORTANT SKILLS TO REMEMBER – LIST THE DATES YOUR CHILD:

FOLLOWED A MOVING TOY WITH EYES

HELD UP HEAD

REACHED FOR AN OBJECT

SMILED

ROLLED OVER

SAT WITHOUT SUPPORT

CRAWLED

IMITATED SOUNDS, SUCH AS “BYE-BYE”

PULLED UP TO A STANDING POSITION

WALKED WITHOUT SUPPORT

PICKED UP FOODS AND TRIED TO FEED SELF

SPOKE FIRST WORD

SPOKE SENTENCES

WALKED UP AND DOWN STAIRS

TOILET TRAINED

PLAYED WITH OTHERS AND SHARED TOYS

TIP: MANY DOCTORS AND NURSES PERFORM DEVELOPMENTAL SCREENINGS.

IF YOUR CHILD HAS A DEVELOPMENT SCREENING DONE, REQUEST A COPY AND FILE IT BEHIND THIS PAGE.

“Expressing our confidence in our children is a powerful way to teach them to be confident in themselves.”

Anonymous

Care Team Contact List

Think of this section as an address book. This section provides forms to keep contact information for your child’s entire care team, including your child’s primary care provider, specialists, pharmacists, and childcare providers.

Below is a table describing the information you should record in each of the forms in this section.



Form	Use this form to record...
PRIMARY CARE PHYSICIAN AND SPECIALISTS	Contact information for your child’s primary care provider and any specialists your child sees, such as: <ul style="list-style-type: none"> » mental health care providers » occupational, physical, or speech therapists » case managers and other service coordinators.
PHARMACIES / MEDICAL SUPPLIERS	Contact information for the pharmacies where you get your child’s medication and supplies.
HOME CARE PROVIDERS	Contact information for any home nursing care providers for your child.
RESPITE CARE PROVIDERS	Contact information for those who provide respite care when you or another care taker needs a break.
CHILD CARE PROVIDERS	Contact information for child care providers.
COMMUNITY RESOURCES AND REFERRALS	Contact and referral information for community resources (such as transportation services to get your child to appointments) and agencies to which your child is referred by a provider (such as WIC).

Primary Care Physician

NAME

ADDRESS/CLINIC

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

Specialist 1

NAME

SPECIALTY

CLINIC/HOSPITAL/AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

DATES CARE BEGAN AND ENDED

OTHER INFORMATION

Specialist 2

NAME

SPECIALTY

CLINIC/HOSPITAL/AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

DATES CARE BEGAN AND ENDED

OTHER INFORMATION

Specialist 3

NAME

SPECIALTY

CLINIC/HOSPITAL/AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

DATES CARE BEGAN AND ENDED

OTHER INFORMATION

Pharmacy 1

NAME

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

HOURS

OTHER INFORMATION

Pharmacy 2

NAME

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

HOURS

OTHER INFORMATION

Medical Supplier 1

NAME

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

HOURS

OTHER INFORMATION

Medical Supplier 2

NAME

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

HOURS

OTHER INFORMATION

Home Care Provider 1

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

START DATE

OTHER INFORMATION

Home Care Provider 2

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

START DATE

OTHER INFORMATION

Home Care Provider 3

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

START DATE

OTHER INFORMATION

Home Care Provider 4

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

START DATE

OTHER INFORMATION

Respite Care Provider 1

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

START DATE

OTHER INFORMATION

Respite Care Provider 2

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

START DATE

OTHER INFORMATION

Respite Care Provider 3

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

START DATE

OTHER INFORMATION

Respite Care Provider 4

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

START DATE

OTHER INFORMATION

Child Care Provider 1

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

START DATE

OTHER INFORMATION

Child Care Provider 2

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

START DATE

OTHER INFORMATION

Child Care Provider 3

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

START DATE

OTHER INFORMATION

Child Care Provider 4

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

START DATE

OTHER INFORMATION

Service 1

CONTACT PERSON

AGENCY

SERVICE PROVIDED

REFERRED BY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

OTHER INFORMATION

Service 2

CONTACT PERSON

AGENCY

SERVICE PROVIDED

REFERRED BY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

OTHER INFORMATION

Service 3

CONTACT PERSON

AGENCY

SERVICE PROVIDED

REFERRED BY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

OTHER INFORMATION

Service 4

CONTACT PERSON

AGENCY

SERVICE PROVIDED

REFERRED BY

ADDRESS

CITY

STATE

ZIP CODE

PHONE ()

FAX ()

OTHER INFORMATION

Health Tracking

This section provides tips and advice about visits to the doctor and forms to use to keep track of doctor visits, test results, medications, treatments, and other information about your child's health care and development. You should also add to this section any notes you get from people providing treatment and services to your child.

On the next page is a table describing the information you should record in each of the forms in this section. Following the table you will find advice on the following topics:

- » General Tips For Medical Appointments
- » Information To Take To Each Appointment
- » Going to the Dentist
- » Information To Get At Each Appointment
- » What To Do If Your Child Is Hospitalized
- » Sample Release of Information Letter

“If we take the time to truly see our children, to listen to what they say, watch what they do, find out how they’re feeling, it will be much easier for us to appreciate their struggles and successes as they learn to work toward a goal.”

Anonymous



Form	Use this form to record...
PHONE CONVERSATIONS & VISITS WITH DOCTORS	The date and results of phone calls and visits with your child's doctor(s).
TEST RESULTS	The date, reason, results, and recommended follow up for your child's hearing and vision tests, lab work, CT scans, MRIs, X rays, and other tests.
HOSPITALIZATIONS AND SURGERIES	The date of any hospitalization, name and location of the hospital, reason for admission, the attending physician, and the discharge date.
HOSPITAL DISCHARGE PLANNING	Any discharge instructions you receive, including information about special care, equipment, and medication.
MEDICATIONS	The name, start/stop dates, dosage, purpose of medication, who prescribed it, and side effects of taking the medication.
TREATMENTS	The date, type, and place where treatment is received, who prescribed it, and follow-up instructions. Examples of treatments include chemotherapy, dialysis, physical therapy, and occupational therapy.
SEIZURE ACTIVITY FORM	The date, time, and seizure-related activity if your child has a seizure.
MEDICAL EQUIPMENT AND SUPPLIES	The type of medical equipment or supplies your child uses, including where you got it, who prescribed it, why, and what your child's response was.
ALLERGY RECORD	Any allergic reactions your child has had, along with medications and instructions you received.
DENTAL CARE RECORD	Dental care your child has received.
GROWTH TRACKING FORM	Your child's age, height, weight, and head circumference.
DAILY DIET TRACKING FORM	Your child's meals and feeding information.
CALENDAR	Dates, times, and locations of appointments.

Health Tracking Advice

GENERAL TIPS FOR MEDICAL APPOINTMENTS

- » Take your child's medical records (diagnostic and surgical reports) when you see new physicians or other healthcare providers.
- » If your child is seen by more than one specialist, be sure that they are each aware of the others' involvement and that they share reports.
- » There may be more than one medical treatment option for your child's condition. Ask what can be expected from each of the possible options. Then decide which treatment you think will be best for your child.
- » If you are uncomfortable about your child's diagnosis or treatment, get a second opinion.
- » If you are not able to understand the medical language used by the doctor, specialist, or other professional, ask him/her to explain it.

INFORMATION TO TAKE TO EACH APPOINTMENT

Before each appointment, prepare information for the doctor regarding your child's health, including:

- » An update of your child's health condition.
- » A description of any new symptoms, and when they began to develop.
- » A description of any improvements or setbacks for ongoing symptoms.
- » A list of any medications being used and any positive or negative effects that you have noted.
- » A list of any questions that you want to ask.

GOING TO THE DENTIST

Before your child is examined, the dentist should have information regarding your child's medical condition and current care. Any precautions recommended by your child's medical specialist should be discussed with the dentist. It is also essential that you provide the dentist with a list of your child's current medications.

INFORMATION TO GET AT EACH APPOINTMENT

Before completing the appointment with a health care provider, be sure that you have all the information you need, including:

- » A clear understanding of the diagnosis and plan for treatment.
- » Instructions for follow-up care (if needed).
- » Lab tests (when, where, and how you will get the results).
- » Medication (type, purpose, dosage, dispensing times, duration, and side effects).
- » Treatment/therapy (type, purpose, location, date, and time).
- » Available support services (agency/organization, address, and telephone).
- » Schedule for referral/follow-up appointment (physician, date, and time).
- » How to reach the physician with questions before the next appointment (name, email, or telephone).

WHAT TO DO IF YOUR CHILD IS HOSPITALIZED

- » Bring your *Complete Care Notebook*.
- » Be sure that your insurance company, HMO, or any third party payer has been notified and complete pre-certification, if necessary.
- » Find out what services the hospital offers to families.
- » Children, especially younger ones, may be unusually clingy or fearful during or following hospitalization. Anticipate this and recognize it as the child's normal emotional response to separation from his or her family.
- » Prepare your child for the experience. Tell your child whether you will be able to stay with him or her overnight, how often you will visit, what his or her room will be like, and what kind of tests or treatment he or she will have. Your child may not be able to absorb all this information at once, so give it in small amounts. Repeat it as often as seems necessary over the course of several days and be ready to answer questions. Many hospitals have orientation programs for children.
- » When possible, stay with your child at the hospital. If you cannot stay with your child in the hospital, visit regularly and as often as possible.
- » At the end of a visit, make your child aware that you are leaving.
- » Before your child's discharge, ask for written instructions from your child's hospital care staff. Write the instructions on the Hospital Discharge Planning form in your *Complete Care Notebook*. Have the hospital care staff watch you performing any special care that will need to be continued when your child returns home, to be sure that you are doing it correctly.

Sample Release of Information Letter

There may be times you wish to get a copy of your child's medical records. Requests for copies of medical records must be put into writing and given to the doctor, hospital, or clinic that has the records.

Below is a Sample Release of Information Letter. This sample letter shows the information that needs to be included in your request. Please note that some healthcare providers may require different information to release your child's records. Make sure to check with the physician or medical facility before sending your request.

June 28, 2004

Dear Dr. Jones:

I, Mary Doe, the parent/legal guardian of Christopher Doe, whose birth date is September 4, 2003, am requesting copies of medical records from Dr. Jones of the Family Medical Center by August 2004.

Please mail this information to the following address:

Mary Doe

165 Oak Street, Apt 2

Providence, RI 01234

Signed,

Parent/Legal Guardian

Date

Hospital Discharge Planning

DISCHARGE INFORMATION	DATE
DOCTOR	
NURSE	SOCIAL WORKER
HOSPITAL NAME	
HOSPITAL ADDRESS	
CITY	STATE ZIP CODE
PHONE ()	FAX ()
WHO WAS PRESENT	

Special Care or Instructions

Equipment Needed

Medication (include dosage and time given)

Seizure Activity Form								
DATE/TIME								
LENGTH OF SEIZURE								
HEAD								
TURNED SIDE TO SIDE								
TURNED LEFT/RIGHT								
STAYED AT MIDLINE								
EYES								
LEFT ROLLED RIGHT/LEFT								
LEFT ROLLED UP/CLOSED								
LEFT STARED								
RIGHT ROLLED RIGHT/LEFT								
RIGHT ROLLED UP/CLOSED								
RIGHT STARED								
BOTH QUIVERED								
MOUTH								
OPENED/CLOSED								
BIT UPPER/LOWER LIP								
SECRETED SALIVA								
BREATHING								
NORMAL								
HELD BREATH SOMETIMES								
LABORED								
CRIED/WHINED								
UNCONSCIOUS								
SKIN COLOR								
NORMAL								
PALE								
RED								
BLUE								
OXYGEN GIVEN								
UPPER LIMBS								
SHIVERED/TREMORS								
JERKED								
STIFFENED/RIGID								
LOWER LIMBS								
SHIVERED/TREMORS								
JERKED								
STIFFENED/RIGID								
HANDS								
OPENED/FISTED								
WITNESSED BY								

Behavior Record

DATE/TIME	BEHAVIOR	TRIGGERS <i>(sleep pattern, activity, people present, diet, etc.)</i>	MEDICATIONS: DOSE & TIME

Daily Diet Tracking Form

DATE	BREAKFAST	LUNCH	DINNER	SNACKS	NOTES

Calendar						
MONTH				YEAR		
SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

“Nothing is a waste of time if you use the experience wisely.”
Auguste Rodin

Daily Routine

Form	Use this form to record...
HOME-BASED MEDICAL HEALTHCARE SCHEDULE	The type of care that is provided to your child and the time it is provided.
GETTING TO KNOW MY CHILD	Information for your child’s care providers, school, and day care staff, including your child’s ability to perform daily activities, cope with stress, communicate with others, express emotions, and any additional information that is important to your child’s character.



This section provides a space for you to record in detail the type and timing of care your child receives, either by you or home-based care providers.

Above is a table describing the information you should record in each of the forms in this section.

Home-Based Medical Healthcare Schedule

Use this form to advise home health providers and caregivers on the type of care your child requires throughout the day

TIME	CARE REQUIRED
DAYTIME	

Getting to Know My Child

ACTIVITIES OF DAILY LIVING

Describe your child's abilities to feed him or herself, bathe, get dressed, use the bathroom, comb hair, brush teeth, etc., including any special routines your child has for these activities. Describe what your child can do by him or herself and any help or equipment your child uses for these activities.

MOBILITY

Describe how your child gets around. Include what your child can do by him or herself and any help or equipment your child uses to get around. Describe any activity limits and any special routines your child has.

COMMUNICATION

Describe your child's ability to communicate and to understand others. Include sign language, words, gestures, or any equipment or help your child uses to communicate or understand others. Include any special words your family and child use to describe things.

REST/SLEEP

Describe your child's ability to get to sleep and sleep through the night. Describe your child's bedtime routine and any security or comfort objects your child uses.

SOCIAL/PLAY

Describe how your child shows affection, shares feelings, or plays with other children. What works best to get your child to get along or cooperate with others? Describe your child's favorite things to do. Include any special family activities or customs.

COPING/STRESS TOLERANCE

What things upset your child? Stressful events might include new people or situations, a hospital stay, or procedures such as having blood drawn. What does your child do when upset or when he or she has “had enough.” Describe your child’s way of asking for help and things to do or say to comfort your child.

RESPIRATORY

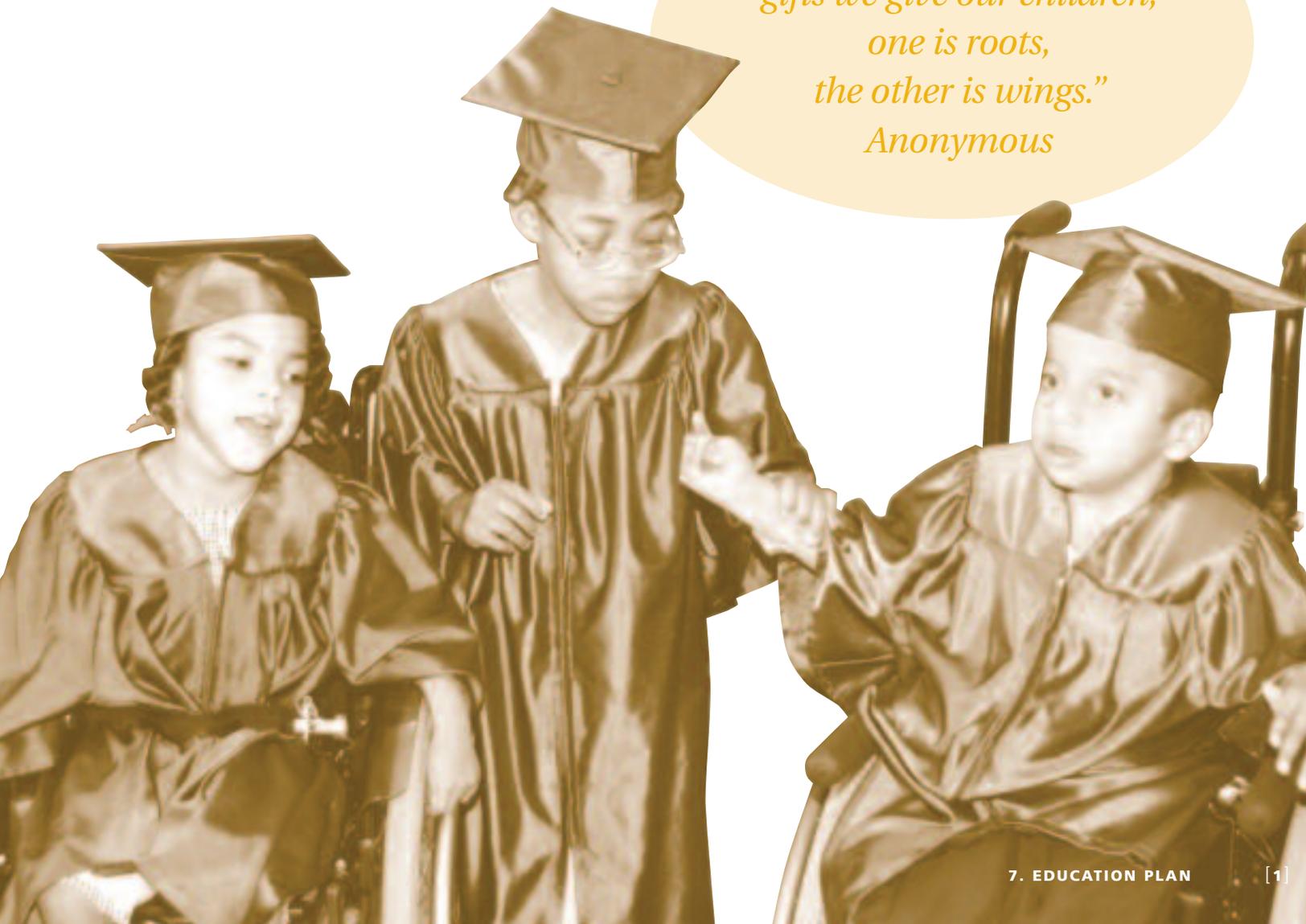
Describe your child’s respiratory (breathing) needs including care or treatments that your child needs and any special techniques or precautions you use when giving care. Include any special routines your child has for respiratory care.

Education Plan

This section provides a form to record the contact information of the schools your child attends throughout his or her childhood. It also contains information about Early Intervention and Special Education services in Rhode Island.

It can also be helpful to keep copies of your child's Individualized Education Plan, school meeting notes, and any other important documents for school records

“There are two lasting gifts we give our children, one is roots, the other is wings.”
Anonymous



Early Intervention and Special Education

WHAT IS EARLY INTERVENTION?

Early Intervention (EI) serves children with developmental delays and their families. The program is for children younger than 3 years old who have a delay in one or more areas of development.

HOW ARE EARLY INTERVENTION AND SPECIAL EDUCATION SERVICES RELATED?

Up until age 3, your child will receive Early Intervention services if he or she is eligible. When your child is 28 months old, you will be asked by EI to sign a release allowing a Special Education services representative from your school district to contact you. Your EI service coordinator will schedule a Transition Planning Meeting with you and a school district representative. Some children leaving EI will not be eligible for Special Education or related services, but every family should be introduced to a Special Education services representative from their school district.

WHAT IS SPECIAL EDUCATION IN RHODE ISLAND?

Special Education programs run in all Rhode Island school districts to provide specially designed instruction to meet the unique needs of a child with a disability. The Rhode Island Department of Education (RIDE) is the state agency responsible for providing these services, which are free for families.

WHAT SERVICES ARE AVAILABLE?

The base of the Special Education program is the Individualized Education Program (IEP). The IEP determines what accommodations, assistive technology, and support from school personnel are required to assist the student with a disability.

Children with disabilities are offered support services, such as:

- » Transportation
- » Speech-language therapy
- » Audiology services
- » Psychological services
- » Physical and occupational therapy
- » Recreation
- » Rehabilitative counseling
- » Medical services

WHAT ARE PARENTS' RESPONSIBILITIES?

It is important to attend your child's IEP meetings every year and to continue to inform your child's school about his or her specific needs.

WHO IS ELIGIBLE FOR SPECIAL EDUCATION?

A child aged 3 to 21 who has been evaluated by a medical professional and has a disability, such as:

- » Autism
- » Behaviorally Challenged
- » Deafness
- » Emotional disturbance
- » Mental retardation
- » Orthopedic impairment
- » Specific learning disabilities
- » Speech or language impairment
- » Traumatic brain injury
- » Visual Impairments

Children aged 3 through 5 can qualify for preschool Special Education and related services when the child is experiencing developmental delay or a disability.

WHO CAN I CONTACT FOR MORE INFORMATION?

Early Intervention

Call the Department of Human Services Information Line at 401-462-5300 and ask for the Early Intervention Program.

Your Local School District
Special Education Coordinator

Look in the blue pages of your phone book or see the Family Voices Resource Guide in Section 9 of this Notebook.

Rhode Island Department of Education
Office of Special Populations

(401) 222-4600 x2504

Rhode Island Parent Information Network

(401) 727-4144

Rhode Island Disability Law Center

(401) 831-3150

“Obstacles don’t have to stop you. If you run into a wall, don’t turn around and give up. Figure out how to climb it, go through it, or work around it.”

Michael Jordan

Expense Tracking

This section provides forms for you to track expenses related to the care of your child. These expenses may be deductible from your annual taxes, so be sure to keep copies of these forms.

Below is a table describing the information you should record in each of the forms in this section.



Form	Use this form to record...
MEDICAL EXPENSE LOG	Billing information related to your child’s medical expenses.
TRAVEL EXPENSE LOG	Places traveled to, miles traveled, and additional expenses while traveling for your child’s health.

Inserted into your child's *Complete Care Notebook* is a copy of the *Family Voices Resource Guide* that provides a full listing of Rhode Island health care services for families of children with special health care needs.

The best way to use this resource is to refer to the *Guide's* table of contents, which lists services by topic and in alphabetical order. Below the topic headings are the names of Rhode Island organizations that provide each specific service.

This guide is updated every year. If you would like an updated copy of the *Family Voices Resource Guide*, contact the Rhode Island Parent Information Network (RIPIN) at 1-800-464-3399.

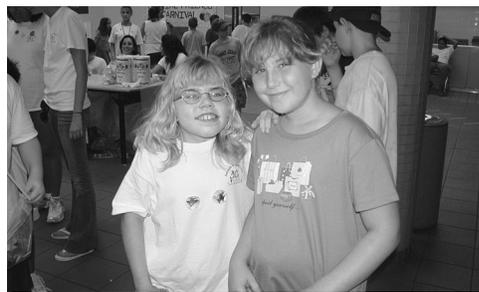
Family Voices Resource Guide



FAMILY VOICES

Resource Guide For Families Of Children with Special Needs

Rhode Island Edition 2006



RHODE ISLAND PARENT INFORMATION NETWORK



175 Main Street Pawtucket, RI 02860
401-727-4144 or 800-464-3399 (RI only)
www.ripin.org or info@ripin.org

Who Are We?

Family Voices

A national grassroots clearinghouse for information and education about ways to improve healthcare for children with disabilities and chronic conditions. The Family Voices network includes families, coordinators in each state and region, and the national staff. Members of the network serve on local, state, and national boards and task forces; as staff for state health agencies or parent organizations; and as advisors to private and public health systems and research projects. Their mission is to bring the family perspective into policy discussions and decisions.

For more information contact:

Family Voices at the Rhode Island Parent Information Network

175 Main Street

Pawtucket, RI 02860

Phone: 401-727-4144

TDD: 401-727-4151

Fax: 401-727-4040

familyvoices@ripin.org

Disclaimer

The information in this directory was obtained using Internet and print materials that were available at the time this directory was being compiled. Wherever possible, phone numbers, mailing addresses, descriptions, contact names, websites and email addresses have been provided. Efforts have been made to ensure that the information is accurate and current at the time of printing. The inclusion of an entry does not constitute an endorsement of the services or products provided by the organization, agency, or individual.

To report changes, add information, make suggestions regarding the format or content, or request copies of this directory, please complete the feedback form provided at the end of this directory and fax (401-727-4040) or mail (Family Voices at RIPIN, 175 Main Street, Pawtucket, RI 02860) it back to us.

Acknowledgements

Family Voices, at the Rhode Island Parent Information Network (RIPIN), would like to acknowledge those who have given their time and thoughtful comments/edits to the production of this Resource Guide for Families of Children with Special Needs.

We sincerely thank the Rhode Island Department of Health, Division of Family Health, for their ongoing support of our work in providing information, education, advocacy, and peer support for children with special needs and their families.

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Early Childhood Services Birth to Five Years of Age

Early Intervention

Early Intervention (EI) serves children ages birth to 36 months who are at risk or have a disability. Anyone can refer to EI.

Part C Program

Rhode Island Department of Health

Division of Family Health

Deb Garneau, Coordinator

Brenda Duhamel, Client Services Coordinator

Cannon Building, Room 302

3 Capitol Hill

Providence, RI 02908-5097

Phone: 401-222-4632

Fax: 401-222-1442

www.health.state.ri.us

Early Intervention Programs

When contacting any site, please ask for the Intake Coordinator of Early Intervention.

Children's Friend and Service

621 Dexter Street

Central Falls, RI 02863

Phone: 401-331-2900

Hasbro Children's Hospital

593 Eddy Street

Providence, RI 02903

Phone: 401-444-3201

James L. Maher Center

24 Hillside Avenue

PO Box 4390

Middletown, RI 02842

Phone: 401-884-2660

Family Resources Community Action

245 Main Street

Woonsocket, RI 02895

Phone: 401-766-0900

J. Arthur Trudeau Memorial Center

250 Commonwealth Avenue

Warwick, RI 02886

Phone: 401-823-1731

or 800-374-1914 (toll free)

or

350 Kingstown Road

Narragansett, RI 02882

401-783-6853

The Groden Center

86 Mount Hope Avenue

Providence, RI 02906

Phone: 401-274-6310

Family Service

55 Hope Street

Providence, RI 02906

Phone: 401-331-1350

Meeting Street

667 Waterman Avenue

East Providence, RI 02914

Phone: 401-438-9500

Early Intervention (EI) Parent Consultant Program

Parent consultants are trained and work through the Rhode Island Parent Information Network. They are placed at each EI site to ensure family-centered practices, hold play groups, coffee hours and provide workshops.

Lisa Schaffran, Early Intervention Program Director

Rhode Island Parent Information Network

175 Main Street

Pawtucket, RI 02860

Phone: 401-727-4144 x153 or 800-464-3399 x153 (toll free in RI only)

Fax: 401-727-4040

www.ripin.org

schaffran@ripin.org

Other Early Intervention Resources

Interagency Coordinating Council (ICC)

Advises and provides assistance to the RI Department of Health on Early Intervention programs

Dawn Wardyga, ICC Chair

Phone: 401-727-4144 x158 or 800-464-3399 x158

Fax: 401-727-4040

Early Intervention Central Directory

Provides basic information about the Early Intervention Program in RI, as well as information about various services available for young children and their families.

Phone: 401-727-4144 or 800-464-3399 (toll free in RI only)

Also available online at: www.ripin.org/centraldirectory.pdf

Early Head Start

Early Head Start is a national program that provides comprehensive developmental services for low-income, preschool children under 3 and social services for pregnant women. Early Head Start focuses on four cornerstones essential to quality programs: child development; family development; community building; and staff development. The purpose of Early Head Start is to: enhance children's physical, social, emotional, and cognitive development; enable parents to be better caregivers of and teachers to their children; and help parents meet their own goals, including that of economic dependence.

Children's Friend and Service

153 Summer Street

Providence, RI 02903

401-276-4300

www.childfriendri.org

C.H.I.L.D., Inc.

160 Draper Avenue

Warwick, RI 02886

401-737-0403

Tri-Town Community Action Program

1126 Hartford Avenue

Johnston, RI 02919

401-351-2750

East Bay Community Action Program

16 Liberty Street

Warren, RI 02885

401-245-2833

New Visions for Newport County

Joel Peckham Center

654 Green End Avenue

Middletown, RI

401-846-5454

Cranston Child Development Center

848 Atwood Avenue

Cranston, RI 02902

401-943-5160

Head Start

Head Start is a national program that provides comprehensive developmental services for low-income, preschool children ages 3 to 5 and social services for their families. Head Start offers specific services that focus on education, social-emotional development, physical and mental health and nutrition.

C.H.I.L.D., Inc.

Director: Lynda Dickinson

Disabilities Coordinator: Michelle

Wolstenholme

Early Head Start Coordinator: Sonya

Murphy

160 Draper Avenue

Warwick, RI 02886

401-737-0403

Providence Head Start

Director: Sister Barbara McMichael/

Mary Dean

Disabilities Coordinator: Debra Saul

20 Almy Street

Providence, RI 02909

401-272-1760

Self Help/East Bay Head Start

Director: Mary Nugent

Disabilities Coordinator: Debbie Keith

Early Head Start Coordinator: Janet

Marquez

16 Liberty Street

Warren, RI 02885

401-245-2833

Children's Friend and Service

Director: Rosemary Soave

153 Summer Street

Providence, RI 02903

401-729-9179

Woonsocket Head Start and Day Care

Director: Karen Bouchard

Disabilities Coordinator: Lisa Caswell

2 Bourdon Boulevard

Woonsocket, RI 02895

401-769-1850

New Visions for Newport County

Director: Cindy Larson

Disabilities Coordinator: Kathy Stack

Joel Peckham Center

654 Green End Avenue

Middletown, RI 401-846-5454

Tri-Town Community Action

Director: Susan Connaughton

Disabilities Coordinator: Julie Bircher

Early Head Start Coordinator: Rhonda Ferrell

1126 Hartford Avenue

Johnston, RI 02919

401-351-2750

Cranston Child Development Center

Head Start and Early Head Start

Director: Jeanne Rheaume

Disabilities Coordinator: Judith Soscia

Early Head Start: Toni Enright

848 Atwood Avenue

Cranston, RI 02902

401-943-5160

South County Community Action Program

Director: Carol Hemingway

Disabilities Coordinator: Heidi Nordman

1080 Kingstown Road

PO Box 3738

Peace Dale, RI 02883

401-789-3016

Child Outreach Screening

Child Outreach Screening is a developmental screening program available to all children ages 3 through 5 offered through each local educational agency. It provides families with information about their child's development and offers information about other resources available in the community. Children are screened in the areas of motor, language, cognition, behavior and socialization, speech, vision and hearing. If concerns emerge as a result of a screening a referral is made to the local school district for a more in-depth evaluation in order to determine eligibility for special education and related services. The Rhode Island Department of Education monitors the Child Outreach Screening program.

Rhode Island Department of Education
Phone: 401-222-4600

Child Outreach Coordinators

Barrington

Stephen Marchetti
283 County Road
Barrington, RI 02806
401-247-3145

Bristol-Warren

Gail Peloquin
151 State Street
Bristol, RI 02806
401-254-5930

Burrillville / Foster / Glocester / North Smithfield / Scituate

Marilyn Lang
23 A Theodore Foster Drive
North Scituate, RI 02857
401-647-7560

Central Falls

Patricia Madden
Registration and Outreach Center
325 Cowden Street
Central Falls, RI 02863
401-727-6177

Chariho

Lisa Neill
455A Switch Road
Wood River Junction, RI 02894
401-364-1160

Coventry

Barbara Bridge
9 Foster Drive
Coventry, RI 02816
401-822-9410

Cranston

Leslie Doonan
45 Sprague Avenue
Cranston, RI 02910
401-785-8006

Cumberland

Kathleen Gibney
2602 Mendon Road
Cumberland, RI 02864
401-722-4434

East Greenwich / New Shoreham / Exeter / West Greenwich / Narragansett / South Kingstown

Julie Wellen
646 Camp Avenue
North Kingstown, RI 02852
401-295-2888

East Providence

Aurora Duarte
80 Burnside Avenue
East Providence, RI 02915
401-433-6216

Jamestown

Peggy Wark
75 Melrose Avenue
Jamestown, RI 02835
401-423-7020

Johnston

Susan Jadosz
10 Memorial Drive
Johnston, RI 02919
401-233-1900 x2439

Lincoln

Muriel DesJardin
1624 Lonsdale Avenue
Lincoln, RI 02865
401-726-1292

Middletown / Newport / Little Compton / Portsmouth / Tiverton / Narragansett / New Shoreham

Ann Marie McAndrews
1 Frank Coelho Drive
Portsmouth, RI 02871
401-683-3570

North Providence

Mary Wojeck
401-233-1100 x123
Centerdale School
11 George Street
North Providence, RI 02911

Pawtucket

Joan Moran Phillips
Creamer Administration Building
Park Place, P.O. Box 388
Pawtucket, RI 02860
401-729-6511

Providence

Elaine Mackio
797 Westminster Street
Providence, RI 02903
401-456-9331

Smithfield

Colleen Payton
49 Farnum Pike
Smithfield, RI 02917
401-231-6608

Warren

Helen Albernaz
151 State Street
Bristol, RI 02806
401-245-1999

Warwick

Alice Freeman
101 Lake Shore Drive
Warwick, RI 02889
401-734-3245

Westerly

Evie Martin
44 Park Avenue
Westerly, RI 02891
401-348-2713

West Warwick

Carole Ogni
401-822-8432
10 Harris Avenue
West Warwick, RI 02893

Woonsocket

Marybeth Wilcox-Ziepniewski
McFee Administration Building
108 High Street
Woonsocket, RI 02895
401-767-4643

Parents As Teachers (PAT)

The Rhode Island Parent Information Network (RIPIN) manages this statewide home visiting program. RIPIN firmly believes that parents are their child's first and best teacher. Through home visits to parents with children from birth to five years of age, families are offered: 1) information on their child's growth and development, 2) access to state and community based resources, 3) opportunities to meet other parents with children of a similar age and 4) annual developmental screenings for their child.

Gladys Tiede, Program Director
Rhode Island Parent Information Network
175 Main Street
Pawtucket, RI 02860
Phone: 401-727-4144 x154 or 800-464-3399 x154 (toll free in Rhode Island only)
Fax: 401-727-4040
tiede@ripin.org
www.ripin.org

Home Instruction Program for Preschool Youngsters (HIPPY)

The Home Instruction Program for Preschool Youngsters (HIPPY) is a statewide visiting program for parents of children from three to five years of age. Offered by the Rhode Island Parent Information Network, HIPPY supports the development of school readiness through cognitive skill building, information about the local school district, parent-networking opportunities, and by connecting families to community resources.

Mary Doyle, Program Director
175 Main Street
Pawtucket, RI 02860
Phone: 401-729-6509

Childcare Programs

Comprehensive Child Care Services Network

Comprehensive Child Care Services is a program that provides comprehensive childcare services to children age 3 through entry into kindergarten and their families. Comprehensive Child Care Services include assessment and individualized planning regarding children's health, early childhood education, children's mental health, and support for children with disabilities, nutrition and family education and empowerment.

Rhode Island Department of Human Services
600 New London Avenue
Cranston, RI 02920
Phone: 401-462-5300

Program Sites

Comprehensive Community Action Program
311 Doric Avenue
Cranston, RI 02910
Phone: 401-467-9610

Children's Network - Meeting Street
667 Waterman Avenue
East Providence, RI 02914
Phone: 401-438-9500

Bay Net - West Bay Community Action Program
218 Buttonwoods Avenue
Warwick, RI 02886
Phone: 401-732-4666 x101

Child Care Connection
25 Blackstone Valley Place
Lincoln, RI 02865
Phone: 401-334-0100

Options for Working Parents

Options for Working Parents helps parents looking for child care and employers looking to set up child care resources for employees. This organization has a statewide computerized file of licensed child care centers, family child care homes, family day care systems, nursery schools, summer camps and after school programs. Options refers parents to child care providers, based on the type of care needed, the location of the facility, and any special amenities needed for the child. There is no fee for this service.

Options for Working Parents

30 Exchange Terrace

Providence, RI 02903

Phone: 401-272-7510 or 800-244-8700

Even Start Family Literacy Program

The purpose of this program is to help families become full partners in their children's education. The four components of this program are designed to provide families with the skills and resources to ensure family self-sufficiency with community involvement and support. The four components of the program are: (1) high quality early childhood education for children birth to seven years old; (2) adult literacy including Adult Basic Education, General Education Development (GED), English as a Second Language (ESL), and job training (3) parenting education and (4) parent involvement.

Areas Served: Central Falls, Dorcas Place (serves Providence), Newport, Pawtucket, Tri-town Community Action (serves Smithfield and Johnston), Woonsocket

Charlotte Diffendale

Rhode Island Department of Education

Rhode Island Even Start Coordinator

255 Westminster Street

Providence, RI 02903

Phone: 401-222-4600 x1-2457

Even Start Coordinators

Newport

Nancy Ryan

Phone: 401-845-8579

Tri-Town Community Action

(Johnston/Smithfield)

Erika Greene

Phone: 401-351-2750

Central Falls

Mario Papitto

Phone: 401-727-7700

Woonsocket

Nancy Giambusso

Phone: 401-765-3678

Pawtucket

Heather Harrison

Phone: 401-729-6293

Dorcas Place (Providence)

Ginny Perelson

Phone: 401-273-8886

Family Outreach Program

The Family Outreach Program supports families and their children during the early years of childhood development. This program offers home visits and follow-up services that are designed to meet a variety of family needs. Through the Family Outreach Program, families and children are linked to community agencies and resources. Pregnant women and families with infants and young children up to age 5 are eligible for services.

Family Outreach Program

Rhode Island Department of Health

3 Capitol Hill, Room 302

Providence, RI 02908

Phone: 401-222-5949

Fax: 401-222-1442

Education

Rhode Island Department of Education

Commissioner: Peter McWalters
255 Westminster Street
Providence, RI 02903
Phone: 401-222-4600 x1-2001
TTD Relay RI:
Fax: 401-222-6030
ride0001@ridoe.net
www.ridoe.net

Rhode Island Department of Education, Office of Special Needs

The Rhode Island Department of Education's Office of Special Needs provides assistance and support to schools and parents in meeting the special education needs of children in RI, including specially designed options to assist students with disabilities to meet performance standards. The Office of Special Needs operates a Consumer Complaint program staffed by legal counsel to ensure programs comply with federal and state regulations. Age of children served by Special Education is 3 years to 21 years of age.

Director: Thomas DiPaola
Department of Education
255 Westminster Street
Providence, RI 02903-3400
Phone: 401-222-4600
TTD Relay RI 800-745-5555
Fax: 401-222-6030
tdipaola@ridoe.net
www.ridoe.net
IEP Hotline: 401-222-4600 x1-2504

Special Education Directors by District

Barrington

Anne De Fanti, Director
PO Box 95283 County Road
Barrington, RI 02806
Phone: 401-247-3145
Fax: 401-245-5003
0034@ride.ri.net

Bristol/Warren

Leslie Neubauer, Director
151 State Street
Bristol, RI 02809
Phone: 401-253-4000 x222
Fax: 401-253-1740
ride4388@ride.ri.net

Burrillville

Julian MacDonnell, Director
92 North Main Street
Pascoag, RI 02859
Phone: 401-568-1307
Fax: 401-568-4111
rid22415@ride.ri.net

Central Falls

Arlene Garrison, Director
21 Hedley Avenue
Central Falls, RI 02863
Phone: 401-727-7707
Fax: 401-727-7722

Chariho (Charlestown, Hopkinton, Richmond)

Marcia Tambellini, Director
455 A Switch Road
Wood River Junction, RI 02894
Phone: 401-364-1100
Fax 401-364-1166

Coventry

Virginia Schutttert, Director
222 MacArthur Boulevard
Coventry, RI 02816
Phone: 401-822-9400 or 401-822-9410
Fax 401-822-9406
rid00958@ride.ri.net

Cranston

John Blackburn, Executive Director,
Pupil Personnel
845 Park Avenue
Cranston, RI 02910
Phone: 401-785-8138
Fax: 401-785-1958
jblackburn@mail.cps.k12.ri.us

Cumberland

Denise Ahern, Director
2606 Mendon Road
Cumberland, RI 02864
Phone 401-658-1600
Fax: 401-658-4620

East Greenwich

Helen O'Hara, Director
111 Pierce Street
East Greenwich, RI 02818
Phone: 401-885-3300
Fax: 401-886-3203
ride9487@ride.ri.net

East Providence

Michael Rock, Director
 80 Burnside Avenue
 East Providence, RI 02915
 Phone: 401-433-6216
 Fax: 401-437-3830

Exeter/West Greenwich

Maureen Decrezenzo, Director
 930 Nooseneck Hill Road
 West Greenwich, RI 02817
 Phone: 401-397-7420
 Fax: 401-392-0109
 decreasm@shmail.ewg.k12.ri.us

Jamestown

Robert Wall, Jr., Director
 55 Lawn Avenue
 Jamestown, RI 02835
 Phone: 401-423-7010
 Fax: 401-423-7012

Johnston

Steven Pereira, Director
 10 Memorial Drive
 Johnston, RI 02919
 Phone: 401-233-1900 x2432
 Fax: 401-233-1907
 rid26993@ride.ri.net

Lincoln

William Anderson
 1624 Lonsdale Avenue
 Lincoln, RI 02865
 Phone: 401-726-1292
 Fax: 401-726-1813
 rid21755@ride.ri.net

Narragansett

Patricia Pezzullo, Director
 25 Fifth Avenue
 Narragansett, RI 02882
 Phone: 401-792-9426
 Fax: 401-792-9429
 rid03429@ride.ri.net

Newport

Linda Martin, Director
 437 Broadway
 Newport, RI 02840
 Phone: 401-847-2100
 Fax: 401-849-0170
 epinto@cityofnewport.com

Newport County Regional (Little Compton, Middletown, Portsmouth, Tiverton)

Donald DeCosta, Director
 1 Frank Coehlo Drive
 Portsmouth, RI 02871
 Phone: 401-683-3570
 Fax: 401-683-3372

New Shoreham

Marie Blackburn, Director
 PO Box 249
 Block Island, RI 02807
 Phone: 401-466-5600
 Fax: 401-466-5610

North Kingstown

Daniel McGregor, Director
 100 Fairway Drive
 North Kingstown, RI 02852
 Phone: 401-268-6451
 Fax: 401-268-6455
 ride2052@ride.ri.net

North Providence

Robert Asekoff, Director
 11 George Street
 North Providence, RI 02911
 Phone: 401-233-1110
 Fax: 401-233-1106
 ride5191@ride.ri.net

North Smithfield/Smithfield

Robert Fricklas, Director
 PO Box 72
 Slatersville, RI 02876
 Phone: 401-766-1868
 Fax: 401-765-
 8764rid23060@ride.ri.net

Northwest Special Education Region (Foster, Glocester, Foster/Glocester, Scituate)

John Magner, Director
 23A Theodore Foster Drive
 North Scituate, RI 02857
 Phone: 401-647-4106
 Fax: 401-647-4107
 jtmagner@hotmail.com

Pawtucket

Cathy Fusco, Director
 Creamer Administration Building
 Park Place
 Pawtucket, RI 02860
 Phone: 401-729-6382
 Fax: 401-727-1641

Providence

Kenneth Swanson, Director
 Robert Lynch, Assistant Director
 797 Westminster Street
 Providence, RI 02908
 Phone: 401-456-9331
 Fax: 401-453-
 8699rid01479@ride.ri.net

Smithfield

Michael Moriarty, Director
 49 Farnum Pike
 Esmond, RI 02917
 Phone: 401-231-6608
 Fax: 401-232-0870
 Email: rid25811@ride.ri.net

South Kingstown

Roseann Lilientha, Interim Director
 307 Curtis Corner
 Wakefield, RI 02879
 Phone: 401-792-9652
 Fax: 401-792-9604
 rid25991@ride.ri.net

Warwick

Steven Lowery, Director
 1849 Warwick Avenue
 Warwick, RI 02889
 Phone: 401-734-3000
 Fax: 401-734-3003

Westerly

Mark Hawk, Director
 44 Park Avenue
 Westerly, RI 02891
 Phone: 401-348-2711
 Fax: 401-348-2707
 hawkm@ride.ri.net

West Warwick

Jeannette Roof-Rothwell
 10 Harris Avenue
 West Warwick, RI 02893
 Phone: 401-822-8432
 Fax: 401-822-8430

Woonsocket

Denise Bloom, Director
 McFee Administration Building
 108 High Street
 Woonsocket, RI 02895
 Phone: 401-767-4600
 Fax: 401-767-4640
 ride4626@ride.ri.net

Metropolitan Career and Technical Center

Danielle DeGennaro-Labbe, Special Education Director
Shepard Building
80 Washington Street
Providence, RI 02903
Phone: 401-277-5046
Fax: 401-277-5049

Special Education Contacts at State Operated Schools

RI Department of Children, Youth, and Families

Colleen Hedden, Project Director
610 Mount Pleasant Avenue
Providence, RI 02908
Phone: 401-457-4871
Fax: 401-457-4511

RI Department of Corrections

Timothy Murphy, Education Unit Administrator
PO Box 8312
Cranston, RI 02920
Phone: 401-464-2507
Fax: 401-464-2509

RI School for the Deaf

Dr. Reginald Redding
1 Corliss Park
Providence, RI 02908
Phone: 401-222-3525
Fax: 401-222-6998

RI Training School

Robert Dumais, Director
300 New London Avenue
Cranston, RI 02920
Phone: 401-464-2061
Fax: 401-464-1464

Davies Career and Technical High School

Vicki Phelps, Special Education Director
Stephen G. Thornton, Principal
Jenckes Hill Road
Lincoln, RI 02865
Phone: 401-728-1500
Fax: 401-728-8910

Metropolitan Regional Career and Technical Center

Dennis Littky, Director
80 Washington Street, Room 436
Providence, RI 02903
Phone: 401-277-5046
Fax: 401-277-5049

Providence Urban Collaborative Accelerated Program (UCAP)

Robert DeBlois, Director
75 Carpenter Street
Providence, RI 02903
Phone: 401-272-0881
Fax: 401-273-7141
www.ucap.org

State Staff Assignments

Each school district is assigned an Education Consultant from the Office of Special Needs as listed below. School district personnel, parents, and any other person needing assistance concerning the assigned school district may contact the Education Consultant assigned to that district for assistance.

General Information: 401-222-3505

District Consultant: dial 401-222-4600 and the following extension

Bristol/Warren/East Providence

Cathy Schulbaum, 1-2316

Burrillville/Central Falls/

Woonsocket

Susan Wood, 1-2309

Chariho

Kim Carson, 1-2336

Coventry/Cranston/Foster/ Gloucester/Scituate/ACI/ Davies Career and Technical Center

David Sienko, 1-2216

Exeter/Narragansett/New

Shoreham/ South

Kingstown/West Greenwich

Amy Cohen, 1-2408

Jamestown/East Greenwich/

Warren/ CVS Highlander

School/RI Training School/ACI

Cathy Schulbaum, 1-2316

Johnston/Lincoln/Cumberland/

North Providence/ Pawtucket/

International Institute School

Ina Woolman, 1-2318

Little Compton/Barrington/

Tiverton/Middletown/

Newport/Portsmouth

Barbara Burgess, 1-2363

North Kingstown/Providence/

The Met School/RI School for

the Deaf

Sally Radford, 1-2315

North Smithfield/Smithfield

Susan Wood, 1-2309

Warwick/Westerly/West

Warwick/Kingston Hill School

Kim Carson, 1-2336

The Autism Support Center

Provides a comprehensive, coordinated system of services to meet the needs of individuals and their families with Autism Spectrum Disorders (ASD). Consulting teams are available to assist school personnel with workshop and in-service programs, consultations, classroom design and curriculum and programming issues. The project also offers an 8-week training series for parents and professionals working with children with ASD in the home.

Sue Constable
Department of Education
Office of Special Needs
255 Westminster Street
Providence, RI 02903
Phone: 401-222-4600 x1-2014
Fax: 401-222-6030
rid23926@ride.ri.net

Vocational Education for Students with Disabilities, RI Transition Project for Youth with Disabilities, State Department of Education

Shepard Building
255 Westminster Street
Providence, RI 02903-3400
Phone: 401-222-4600 x1-2216

GED Administration

Robert Mason
Department of Elementary and Secondary Division
Shepard Building
255 Westminster St.
Providence, RI 02903-3414
Phone: 401-222-4600 x1-2180
www.ridoe.net

Rhode Island Association of Private Special Education Schools (RIAPSES, Inc)

RIAPSES is a group of specialized educational programs that work collaboratively with RI public schools. All of the programs are approved by the RI Department of Education. These programs exist to meet a variety of intensive needs for students and their families by providing full time placements, joint services, and consultation in a variety of settings. The following schools are part of RIAPSES.

St. Andrew's School

John D. Martin, Headmaster
Audrey Lacher-Katz, Director of
Special Education
63 Federal Road
Barrington, RI 02806-2407
401-246-1230

Cornerstone School

Kenneth W. Andrew
665 Dyer Avenue
Cranston, RI 02920
401-942-2388

NFI/ACE Program

Mary Anne McIntyre, Director of
Special Education
735 New London Avenue
Cranston, RI 02920
401-946-2020

Valley Community School

James L. DePasquale, Principal
Alan N. Cafferty, Director of Special
Education
83 Rolfe Street
Cranston, RI 02910
401-941-9707

Emma Pendleton

Dr. Kevin P. Myers, Director of Special
Education
Bradley Hospital
1011 Veterans Memorial Parkway
East Providence, RI 02915
401-432-1130

Meeting Street School

Pat Ferri, Director of Educational
Programs/Director of Special
Education
667 Waterman Avenue
East Providence, RI 02914
401-438-9500

Camp E-Hun-Tee

Dr. O. William Hilton, Jr., Director of
Special Education
One Camp E-Hun-Tee Place
Exeter, RI 02822
401-539-7775

Harmony Hill School, Inc.

Terrence J. Leary
Ann Marie Dubuque, Director of
Special Education
63 Harmony Hill Road
Chepachet, RI 02814
401-949-0690

The Spurwink School II

Raymond A. Arsenault
Carleen Bellaire, Director of Special
Education
365 River Road
Lincoln, RI 02865
401-334-2222

Valley Community School

James L. DePasquale, Principal
Kathleen G. Weber, Director of Special
Education
60 Hammarlund Way
Middletown, RI 02842
401-849-7452

Ocean Tides, Inc.

Jane E. Genereux, Principal
Marjorie J. Hanson, Director of Special
Education
635 Ocean Road
Narragansett, RI 02882
401-789-1016

James L. Maher School

John H. Maher
Barbara S. Schiaroli, Director of
Special Education
120 Hillside Avenue
Newport, RI 02840
401-846-3518

George N. Hunt Campus School

Bernard J. Smith
Cindy Turbitt, Director of Special
Education
St. Mary's Home for Children
440 Fruit Hill Avenue
North Providence, RI 02911
401-353-3900 x311

Valley Community and Day School

James L. DePasquale, Principal
Cynthia Houston, Director of Special
Education
249 Roosevelt Avenue
Pawtucket, RI 02860
401-722-3513

Tides Learning Center

Brother Michael Reis
Michael J. Capalbo, Director of Special
Education
242 Dexter Street
Pawtucket, RI 02860
401-724-8060

The Bradley School

Dr. Kevin P. Myers, Director of Special
Education
2836 East Main Road
Portsmouth, RI 02871
401-682-1816

Center for Individualized Training and Education

Laurel M. Scorpio, Program
Director/Director of Special
Education
15 Bough Street
Providence, RI 02909
401-351-0611

Metropolitan Career and Technical Center

401-277-5046
Downtown Campus
Danielle DeGennaro-Labbe, Director
of Special Education
80 Washington Street
Providence, RI 02903
Peace Street Campus
Danielle DeGennaro-Labbe, Director
of Special Education
362 Dexter Street
Providence, RI 02907

Mount Pleasant Academy

Joan L. Colwell, Director of Special
Education
1246 Chalkstone Avenue
Providence, RI 02909
401-521-4335

**North American Family Institute
Alternatives Program**

Robert Dumais, Director of Special
Education
350 Duncan Drive
Providence, RI 02906
401-453-4740

Ocean Tides School

Marjorie J. Hanson, Director of Special
Education
260 Highland Avenue
Providence, RI 02906
401-861-3778

**Pathways Strategic Teaching
Center of Kent County RIARC**

Margaret Deslaurier
401-739-2700

Rhode Island School for the Deaf

Dr. Reginald Redding, Principal
1 Corliss Park
Providence, RI 02908
401-222-3525

School One

Denise M. Jenkins
Dr. Janice DeFrances, Director of
Special Education
220 University Avenue
Providence, RI 02906-5434
401-331-2497

Tavares Pediatric Center

Eugene F. Tavares, Administrator
Danielle DeGennaro-Labbe, Director
of Special Education
101 Plain Street
Providence, RI 02903
401-272-7127

The Groden Center, Inc.

Dr. June Groden and Dr. Gerald Groden,
Co-Directors
William Anderson, Director of Special
Education
86 Mount Hope Avenue
Providence, RI 02906
401-274-6310

The Providence Center School

Martha Morris, Principal/Director of
Special Education
520 Hope Street
Providence, RI 02906
401-276-4000

Tides Learning Center

Brother Michael Reis
Michael J. Capalbo, Director of Special
Education
790 Broad Street
Providence, RI 02905
401-467-8228

**Turning the Corner School
Program**

Denise Bloom, Interim Director of
Special Education
58 Dartmouth Street
Providence, RI 02907
401-785-8446

Vocational Resources, Inc.

Paul Pickens
Robert M. Sherman, Director of
Special Education
100 Houghton Street
Providence, RI 02904
401-861-2080

South Shore School

Kenneth Andrews, Acting Director of
Special Education
730 Kingstown Road
Wakefield, RI 02879
401-783-1150

Eleanor Briggs School

Barbara A. Dickerson, Director of
Special Education
116 Long Street
Warwick, RI 02886
401-732-1540

**Francis B. Sargent Rehabilitation
Center**

Marilyn F. Serra
800 Quaker Lane
Warwick, RI 02818
401-886-6600

Trudeau Education Services

Richard Patterson
Director of Special Education
3445 Post Road
Warwick, RI 02886

Tides Learning Center

Dr. Michael Reis
Michael J. Capalbo, Director of Special
Education
222 Washington Street
West Warwick, RI 02893
401-739-2700

New Pride School/Hillside

James D. Williams
Denise Bloom, Interim Director of
Special Education
115 Ricard Street
Woonsocket, RI 02895
401-762-0769

**The ARC of Northern Rhode
Island**

Gerald P. Ventre
Mary Ellen Dubuc, Director of Special
Education
80 Fabien Street
Woonsocket, RI 02895
401-769-9720

Viola M. Berard School

James V. Gallagher, Director of Special
Education
181 Cumberland Street
Woonsocket, RI 02895-0856
401-766-3330 x7148

Transition to Adult Life

For students with special needs who have an Individualized Education Plan (IEP) and who are age fourteen or older, planning for their life after high school must be part of their IEP. This is called Transition Planning. The transition planning process can be complex and involve many issues. A good overview of the transition planning process and related issues is the publication, Here's to Your Student's Future! A Parent's Guide to Transition Planning. You can receive a copy of this guidebook and other information for families on Transition Planning by calling: Rhode Island Parent Information Network at 401-727-4144 x125 or 800-464-3399 x125

Regional Transition Centers

The RI 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 Committees (TAC).

The Transition Centers also house the Regional Vocational Assessment Centers. These centers provide vocational assessment services for students in special education ages 14-21 who are eligible for the services of the Office of Rehabilitation Services (ORS). The Assessment Centers assist students with their personal career goals through career counseling, vocational testing and community based work experiences. Information from the assessment is shared with the IEP teams and used to set IEP goals for employment, post-secondary education and training, community participation and independent living. Referrals are made by IEP Teams or directly through the Office of Rehabilitation Services (ORS).

East Bay

Coordinator: Carolyn Aspinwall
317 Market Street
Warren, RI 02885-2637
Phone: 401-245-2045 x303
Fax: 401-245-9332

Northern Rhode Island

Coordinator: Jane Slade
2352 Mendon Road
Cumberland, RI 02864-3715
Phone: 401-658-5790
Fax: 401-658-4012

Other Transition-Related Resource

Paul Sherlock Center on Disabilities
Rhode Island College
600 Mt. Pleasant Avenue
Providence, RI 02908
Phone: 401-456-8072
www.uapri.org

West Bay

Coordinator: Rosemary Lavigne
144 Bignall Street
Warwick, RI 02888-1005
Phone: 401-941-8353 x16
Fax: 401-941-8535

Southern Rhode Island

Coordinator: Alice Woods
646 Camp Avenue
North Kingstown, RI 02852
Phone: 401-295-2888
Fax: 401-295-3232

Supported Employment (State Agencies which contract Supported Employment)

RI Department of Human Services, Office of Rehabilitative Services (ORS)

40 Fountain Street
Providence, RI 02903
Phone: 401-421-7005
TDD: 401-421-7016
www.ors.state.ri.us

RI Department of Mental Health, Retardation, and Hospitals

Division of Developmental Disabilities, Division of Integrated Mental Health Services

Barry Hall
14 Harrington Road
Cranston, RI 02920-3080
Phone: 401-462-3291
TDD: 401-462-6087
www.mhrh.state.ri.us

Vocational Resources, Inc.

VRI's mission is to provide services that expand vocational and economic opportunities for people with disabilities and related challenges in order to enhance their capacity for independent living, increased quality of life, and work.

Vocational Resources, Inc.

100 Houghton Street

Providence, RI 02904

Phone: 401-861-2080

TTY: 401-331-2830

Fax: 401-454-0889

Satellite offices:

Kingston: 401-782-0022; 401-782-1346 (TTY)

Newport: 401-849-6888

Parents and Friends for Alternate Living (PAL)

Supports people with a disability and their families as they advocate for themselves. It promotes individual direction and supports through a variety of demonstration projects to provide respite and recreation opportunities to Rhode Islanders who have a disability and their family members.

Doreen McConaghy, Executive Director

Parents and Friends for Alternate Living

PO Box 8885

Cranston, RI 02920

Phone: 401-785-2100

Fax: 401-785-2186

Email: PAL@IDS.net

Developmental Disabilities

The Division of Developmental Disabilities

PO Box 20523
Cranston, RI 02920
Phone: 401-462-3234
Social Service: 401-462-3234
Quality Assurance: 401-462-2629
TDD: 401-462-6087
Fax: 401-462-6189
www.mhrh.state.ri.us

Rhode Island ARC

99 Bald Hill Road
Cranston, RI 02920
Phone: 401-463-9191

National Association of Developmental Disabilities Councils (NADDC)

The NADDC provides support and assistance to member Councils. The NADDC promotes national policy that provides persons with developmental disabilities the opportunity to make choices about the quality of their lives and to be included in the community.

National Association of Developmental Disabilities Councils (NADDC)
1234 Massachusetts Avenue, NW, Suite 103
Washington, DC 20005
Phone: 202-347-1234
Fax: 202-347-4023
NADDC@igc.apc.org
www.igc.org/NADDC

Rhode Island Developmental Disabilities Council

The Rhode Island Developmental Disabilities Council was established in 1971 by a federal law that requires all states to have planning councils. The Council has 24 members who are appointed by the Governor. Most members are people with developmental disabilities or relatives or guardians of people with developmental disabilities. Other members represent state and private agencies that provide services to people with disabilities. The Council works to make Rhode Island a better place for people with developmental disabilities to live, work, go to school, and be part of the community. Council members come together to discuss issues, solve problems, and plan for better services. The Council also involves people in the community in its planning. The Council is dedicated to improving the independence, productivity, integration, and inclusion of people with developmental disabilities.

Marie Citrone, Executive Director
400 Bald Hill Road Suite 515
Warwick, RI 02886
Voice/TDD: 401-737-1238
Fax: 401-737-3395
riddc@riddc.org
www.riddc.org

Developmental Disabilities Councils of Other States in the Region

Connecticut Developmental Disabilities Council

460 Capitol Avenue
Hartford, CT 06106-1308
Phone: 860-418-6160
TTY: 860-418-6172
Fax: 860-418-6003
www.state.ct.us/ctcdd

Maine Developmental Disabilities Council

Nash Building
139 State House Station
Augusta, ME 04333-0139
Phone: 207-287-4213
Fax: 207-287-8001

Massachusetts Developmental Disabilities Council

174 Portland Street, 5th Floor
Boston, MA 02114
Phone: 617-727-6374 x108
TTY: 617-727-1885
www.state.ma.us/mddc

New Hampshire Developmental Disabilities Council

The Concord Center
10 Ferry Street Unit 315
Concord, NH 03301-5004
Phone: 603-271-3236 or 800-735-2964 (toll free/TDD)
Fax: 603-271-1156

Vermont Developmental Disabilities Council

103 South Main Street
Waterbury, VT 05671-0206
Phone: 802-241-2612 or 888-317-2006 (toll free/TDD)
www.ahs.state.vt.us/vtddc

University Affiliated Programs

Authorized by Federal legislation to help states and local communities respond to the needs of people with developmental disabilities and their families, University Affiliated Programs (UAPs) serve as a liaison between the academic world and the developmental disabilities service delivery system. UAPs network with and provide assistance to state agencies, their local affiliates, and to various nongovernmental, consumer-based organizations.

American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP)

8630 Fenton Street, Suite 410
Silver Spring, MD 20910
Phone: 301-588-8252
Fax: 301-588-2842
info@aaup.org
www.aaup.org

Paul V. Sherlock Center on Disabilities

Rhode Island College
Institute for Developmental Disabilities
600 Mount Pleasant Avenue
Providence, RI 02908
Phone: 401-456-8072
Fax: 401-456-8150
TTY: 401-456- 8773
www.uapri.org

Vocational Assessment and Placement

Groden Center

86 Mount Hope Avenue
Providence, RI
Phone: 401-274-6310

Vocational Resources, Inc./Goodwill

100 Houghton Street
Providence, RI
Phone: 401-861-2080

Vocational Rehabilitation Services

Empowers individuals with disabilities to choose, prepare for, obtain and maintain employment; economic self-sufficiency, independence, and integration into society. Program Disability Determination Services.
Raymond A. Carroll, Administrator
Department of Human Services, Office of Rehabilitation Services
40 Fountain Street
Providence, RI 02903
Phone: 401-421-7005 x301
rcarroll@ors.state.ri.us
www.ors.state.ri.us

Wise Voices (State Run Group Homes)

DDD @MHRH RI Community Living and Support
c/o RICLAS
Simpson Hall
PO Box 20523
Howard Avenue
Cranston, RI 02920
Phone: 401-462-2796

Transportation Resources

RIDE - RIPTA Para Transit Service

ADA Americans with Disabilities Act Transit Program Copies of RIPTA's current program for people with disabilities are available in large print, Braille or on audiotape by calling. Also offered is Flex Service, which is service for suburban and rural areas that have little or no fixed route service. You must call 48 hours in advance.

265 Melrose Street
Providence, RI 02907
Phone: 401-784-9500 x153
TDD: 401-784-9524
www.ripta.com

PARI Independent Living Center

500 Prospect Street
Pawtucket, RI 02860
Voice/TDD: 401-725-1966
Fax: 401-725-2104

OSCIL (Ocean State Center for Independent Living)

59 West Shore Road
Warwick, RI 02889
Phone: 401-738-1013
TDD: 401-738-1015
Fax: 401-738-5118
Hispanic Program: 401-738-5118
Kingston Office: 401-782-9400
www.oscil.org

Assistive Technology and Technology Access

Tech ACCESS Center of Rhode Island

A private, nonprofit resource center that serves people with disabilities who are interested in assistive technology. Assistive Technology is any device that helps a person with a disability function better at home, work, school, or in the community. Information and Referral Services regarding assistive technology products, funding, and services are provided at no charge. Tech ACCESS also provides referrals to service providers, vendors, protection and advocacy services, etc.

100 Jefferson Boulevard
Warwick, RI 02888
Voice/TYY: 800-916-8324
Fax: 401-463-3433
techaccess@techaccess-ri.org
www.techaccess-ri.org

Rhode Island Assistive Technology Access Partnership

The intent of the partnership is to bring about systems change through a comprehensive, consumer-responsive partnership of RI resources to maximize the timely delivery of appropriate assistive technology devices and services to Rhode Islanders with disabilities of all ages. The partnership includes special emphasis on minorities, the poor, and limited-English speaking populations.

Rhode Island Assistive Technology Access Partnership
Office of Rehabilitation Services
40 Fountain Street
Providence, RI 02903
English: 401-421-7005 x310
Spanish: 401-272-8090
Cambodian: 401-272-7990
TTY: 401-421-7016
Fax: 401-421-9259
www.atap.state.ri.us

Other Education Resources

Rhode Island Parent Information Network

175 Main Street
Pawtucket, RI 02860
Phone: 401-727-4144 or 800-464-3399 (toll free in Rhode Island only)
Fax: 401-727-4040
www.ripin.org

Parent Support Network

400 Warwick Avenue
Warwick, RI 02886
Phone: 401-467-6855 or 800-483-8844 (toll free)

Parent Teacher Association (PTA)

RIC Campus-Building #6
600 Mt. Pleasant Avenue
Providence, RI 02908
Phone: 401-272-6405
ri_office@pta.org

Special Education Resource and Service

www.specialeducation.org

Rhode Island Parents' Paper

www.parenthoodweb.com

Assistive Technology in Education

at-advocacy.phillynews.com/index.html

Health

The following is a listing of systems that encompass health related services and issues. Please remember that this is a guide and that all services may not be available to all families. Call the specific agency or group for detailed information.

Rhode Island Department of Health, Division of Family Health

Family Health Information Line

The Family Health Information Line is a toll-free telephone service for anyone who needs information about programs and services to improve the health of families and their children. A bilingual information specialist can answer questions about the following programs and services: Women Infants and Children Program (WIC); immunizations; the Early Intervention Program; lead poisoning prevention; parenting; adolescent health; family planning; Medical Assistance; Food Stamps; etc. If the information specialist cannot answer the question(s), referrals are made to community agencies.

3 Capitol Hill, Room 302

Providence, RI 02908

800-942-7434

Programs for Children with Special Health Care Needs

Department of Health, Office for Families Raising Children with Special Health Care Needs

Chief: Deborah Garneau

3 Capitol Hill

Providence, RI 02908

Phone: 401-222-5929

www.health.state.ri.us

Rhode Island Medical Assistance Program

This federal and state funded program, also known as Medicaid, pays for health care services for eligible children and families, individuals with disabilities and the elderly. The Department of Human Services administers the RI Medical Assistance Program.

Rhode Island Department of Human Services, Center for Child and Family Health

600 New London Avenue

Cranston, RI 02920

English: 401-462-1300

Spanish: 401-462-1500

TDD: 401-462-3363

Medical Assistance Benefits

The following benefits are covered by the Medical Assistance Program for eligible children:

- Physician's office visits
- Prescription drugs
- Medical tests
- Vision care (eyeglasses, eye exams)
- In-patient hospital care
- Out-patient hospital care
- Physical therapy
- Occupational therapy
- Speech therapy
- Mental health services
- Substance abuse treatment
- Visiting nurse services
- Dental services for children

Some Medical Assistance benefits that are covered require prior authorization by the Department of Human Services. They include the following:

- Durable Medical Equipment
- Home-based Therapeutic Services
- Pediatric Home Care Services
- Skilled Nursing Services
- Certified Nursing Assistant Services

Dental Services For Children

Dental Services is a Medical Assistance benefit which covers children up to 21 years of age.

Preventive Dental Care includes:

- 2 cleanings per year
- Sealants
- Fillings as necessary
- X-rays

Other Dental Services as medically necessary (most require prior approval)

- Orthodontics

How to Apply for Services

No application is necessary. Families should contact the dentist(s) in their area to see if they accept Medical Assistance coverage for payment.

Katie Beckett Provision

This provision provides Medicaid coverage to certain children under the age of 18 who have disabling conditions and live at home. This enables children with disabilities to be cared for at home instead of in an institution.

Eligibility

Certain children under the age of 18 who live at home may be eligible for Medical Assistance benefits/coverage through the Katie Beckett provision. The cost of care provided at home must be less than what Medical Assistance would pay if the child was in a hospital or other institutional setting. Parents' resources are not counted when determining a child's eligibility.

How to Apply for Services

If the child requires medical supports (oxygen, feeding tubes, monitors, frequent or lengthy hospitalizations), apply to: Rhode Island Department of Human Services, Long Term Care Unit. See the next page or www.dhs.state.ri.us for the DHS' local office directory, under "Program: Long Term Care."

Department of Human Services, Local Offices

When applying for Katie Beckett/Medicaid Assistance applicants should call their local DHS Office for their town.

Providence and North Providence

Providence Regional Family Center
206 Elmwood Avenue
Providence, RI 02909
Phone: 401-222-7000
Fax: 401-222-7372

*Bristol, Jamestown, Little Compton,
Middletown, Newport, Portsmouth, Tiverton*
Newport Family Center
110 Enterprise Center
Newport, RI 02840
Phone: 401-849-6000
Fax: 401-849-9066

*Charlestown, Coventry, Cranston, East
Greenwich, Exeter, Foster, Hopkinton,
Johnston, Narragansett, New Shoreham,
Scituate, Richmond, South Kingstown,
Warren, Westerly, West Warwick, Warwick,
West Greenwich*
Benjamin Rush Building
55 Howard Avenue
Cranston, RI 02920
Phone: 401-462-5182
Fax: 401-462-3034

Burrillville, Cumberland, Glocester, Lincoln,

North Smithfield, Smithfield, Woonsocket
Woonsocket Family Center
450 Clinton Street
Woonsocket, RI 02895
Phone: 401-235-6300
Fax: 401-235-6479

*Barrington, East Providence, Central Falls,
Pawtucket*
Benjamin Rush Building
55 Howard Avenue
Cranston, RI 02920
Phone: 401-462-5248
Fax: 401-462-5255

Supplemental Security Income (SSI)

This is a federal program that provides monthly cash benefits to individuals, including children with a physical, developmental and/or mental impairment that results in "marked and severe functional limitations." If a child is eligible for Supplemental Security Income (SSI) benefits in RI, he/she is also eligible to receive Medical Assistance benefits.

Eligibility

Children under the age of 18 with a physical, developmental and/or mental impairment may be eligible if their family also qualifies 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.

How to Apply for Services

Call or visit the local Social Security Office. Information is available by phone in both English and Spanish.

District Manager

Social Security Office

380 Westminster Street, Room 318

Providence, RI 02903

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

Fax: 401-528-4698

Regional Offices

55 Broad Street

Pawtucket, RI 02860

Phone: 401-724-9611 or 800-772-1213

30 Quaker Lane, 1st Floor

Warwick, RI 02886-0111

Phone: 401-822-1463 or 800-772-1213

Post Office Building

127 Social Street

Woonsocket, RI 02895

380 Westminster Mall, Room 318

Providence, RI 02903

Phone: 401-528-4501 or 800-772-1213

130 Bellevue Avenue

Newport, RI 02840

Durable Medical Equipment

A benefit in the Medical Assistance Program available for children from birth to 21 years of age if medically necessary. Durable Medical Equipment (DME) is equipment or devices used for medical/rehabilitative purposes in the home or community. Prior authorization is required.

Examples of Durable Medical Equipment include:

- Wheelchairs
- Walkers
- Specialized strollers
- Crutches
- Hospital beds
- Feeding chairs
- Portable ramps
- Oxygen and home-based therapy equipment
- Assistive technology
- Cardiac monitors
- Hearing aids
- Apnea monitors

Devices Not Covered by RI Medical Assistance Program

- Devices or equipment permanently attached to a structure
- Air conditioners
- Swimming pools
- Whirlpools

How to Apply for Services

For children on Medical Assistance, families can call a durable medical equipment vendor who participates in the RI Medical Assistance Program. The vendor will evaluate the child's need and coordinate getting the necessary documentation to the Department of Human Services for review and approval.

Tech ACCESS Center of Rhode Island

Tech ACCESS of RI is a private, not for profit resource center that serves people with disabilities who are interested in assistive technology. Assistive Technology is any device that helps a person with a disability function better at home, work, school, or in the community. Information and Referral Services regarding assistive technology products, funding, and services are provided at no charge. Tech ACCESS also provides referrals to service providers, vendors, protection and advocacy services, etc.

100 Jefferson Boulevard
Warwick, RI 02888
Voice/TYY: 800-916-8324
Fax: 401-463-3433
techaccess@techaccess-ri.org
www.techaccess-ri.org

Rhode Island Assistive Technology Access Partnership

Office of Rehabilitation Services
40 Fountain Street
Providence, RI 02903
Phone: 401-421-7005 x310
TTY: 401-421-7016
Fax: 401-421-9259
Website: www.atap.state.ri.us
Cambodian: 401-272-7990
Spanish: 401-272-8090

Adaptive Equipment Recycling Program

The Adaptive Equipment Recycling Program at PARI provides adaptive equipment to those unable to afford new equipment. They receive used equipment by donation, restore it to useful condition, modify/adapt it according to need, and then offer the recycled product at reasonable cost to the consumer. The PARI Adaptive Equipment Recycling Programs inventory often includes wheelchairs, walkers, quad canes, forearm/platform/auxiliary crutches, lap boards, slide boards, tub transfer chairs, Gerry chairs, bedside tables, commode frames, shower chairs, bathroom safety equipment, and hearing aids.

PARI Independent Living Center
500 Prospect Street
Pawtucket, RI 02860
Voice/TDD: 401-725-1966
Fax: 401-725-2104

Adaptive Telephone Loan Equipment Program (ATEL)

The ATEL Program loans telephone equipment to residents of the State of Rhode Island who have hearing, speech, or neuromuscular (unable to dial or hold a receiver) impairments. To receive equipment the person must be a resident of Rhode Island, have a speech, hearing, or neuromuscular impairment, and have a single party telephone line. A certificate of disability must be completed and signed by a doctor, a qualified staff member of the Office of Rehabilitation Services, a speech pathologist, an audiologist, or a qualified staff member of the RI School for the Deaf (if the applicant attends or has attended the school).

Stacey A. Conca-Monfils, Program Coordinator
Adaptive Telephone Loan Equipment Program (ATEL)
Vocational Resources, Inc.
100 Houghton Street
Providence, RI 02904
Phone: 401-861-6677 (TDD) or 401-276-0875 (voice/relay)
Fax: 401-454-0889
Website: www.riatelprogram.org
Email: smonfils@riatelprogram.org

National Technical Assistance Center (NTACT)

www.nasmhpd.org/ntac

Adaptive Environments Center, Inc.

374 Congress Street, Suite 301

Boston, MA 02210

Voice/TTY: 617-695-0085 or 800-949-4232

Fax: 617-482-8099

adaptive@adaptenv.org

www.adaptenv.org

CEDARR (Comprehensive Evaluation, Diagnosis, Referral and Re-evaluation)

Mission: All Rhode Island children and their families have an evolving, family-centered, strength based system of care, dedicated to excellence, so they can reach their full potential and thrive in their own communities.

CEDARR Family Centers offer families information on specific disabilities, treatment options and referrals to community supports and assistance.

CEDARR Family Centers

About Families

32 Branch Avenue

Providence, RI 02904

401-331-2700

Family Solutions

134 Thurbers Avenue, Suite

102

Providence, RI 02905

401-461-4351 or 800-640-7283

Families First

Hasbro Children's Hospital,
Room 120

593 Eddy Street

Providence, RI 02903

401-444-7703

Easter Seals

5 Woodruff Avenue

Narragansett, RI 02882

401-284-1000

Home-Based Therapeutic Services

Home-Based Therapeutic Services are a Medical Assistance benefit that provides intense, individualized services to children with severe behavioral health and/or developmental disorders. Services are individualized and are provided in the child's home and community by trained professionals.

How to Apply for Services

Apply for HBTS through CEDARR Centers. See above.

General Health Resources

This section contains resources available to everyone via the Internet or phone. Many of these are nationwide agencies.

American Academy of Pediatrics, RI Chapter

www.riaap.org

Centers for Disease Control

www.cdc.org

Dr. Koop's Community

www.drkoop.com

HealthAnswers

www.healthanswers.com

Healthatoz

Search engine for health and medicine

www.healthatoz.com

Healthfinder

Gateway consumer health information website from the US government

www.healthfinder.gov

HealthGate

www.3healthgate.com

Joint Commission on Accreditation of HealthCare Organizations (JCAHO)

www.jcaho.org

Lifespan

www.lifespan.org

Medline Fool!

www.medportal.com

Medline Plus Health Information

www.nlm.nih.gov/medlineplus

MedSeek

medseek.com

National Institutes of Health (NIH)

www.nih.gov

RI Department of Business Regulation, Insurance Regulation Division

233 Richmond Street

Providence, RI 02903

Phone: 401-222-2223

www.dbr.state.ri.us

Sexual Health Network

sexualhealth.com

Prescription Medication Information

CenterWatch

Clinical trials listing service
www.CenterWatch.com

Pain.com

Information on pain management
www.pain.com

RxList

www.rxlist.com

Affording Care: Free Medications

www.thebody.com/afford/free.html

Directory of Prescription Drug Patient Assistance Programs

www.phrma.org/patients

The Medicine Program

www.medicinprogram.com

Needy Meds

Pharmaceutical manufacturer's drug assistance programs
www.needymeds.com

RxAssist

Obtain comprehensive information on pharmaceutical manufacturers' drug assistance programs.
www.rxassist.org

RIte Care

RIte Care is Rhode Island's Medicaid managed care program that provides health insurance to eligible uninsured pregnant women, parents and children up to age 19. Families receive their health care through participating Health Plans. RIte Care's participating Health Plans include: Neighborhood Health Plan of Rhode Island; Blue CHiP; and United Healthcare of New England.

Eligibility

Eligibility is based on family size and income.

- Pregnant women with family incomes less than 350% of the federal poverty level
- Families with children up to age 18 with family incomes less than 185% of the federal poverty level
- Children younger than 19 with family incomes less than 250% of the federal poverty level

Enrollment of Children with Special Needs into RIte Care

Many children with special needs who have Medical Assistance coverage (Medicaid) currently receive services through Medicaid "Fee-For-Service." This means that the Medical Assistance Program pays providers for each covered service or benefit. Most children with special needs are eligible for Medical Assistance (Medicaid) if they are found eligible for one of the following:

- SSI (Supplemental Security Income)
- Katie Beckett (a special provision in Medicaid)
- DCYF adoption subsidy

Some children with special needs who are currently receiving Medicaid "Fee-For-Service" will be enrolled in RIte Care, Rhode Island's Medicaid managed care program, in the near future.

Cost to Child or Family

Cost-sharing applies for children and pregnant women whose gross family income is greater than 185% of the federal poverty level.

Federal Poverty Level Guidelines (Annual Gross based on 2003 FPL)

	100%	120%	133%	135%	150%	175%	185%	200%
1	8,980.00	10,776.00	11,943.40	12,123.00	13,470.00	15,715.00	16,613.00	17,960.00
2	12,120.00	14,544.00	16,119.60	16,362.00	18,180.00	21,210.00	22,422.00	24,240.00
3	15,260.00	18,312.00	20,295.80	20,601.00	22,890.00	26,705.00	28,231.00	30,520.00
4	18,400.00	22,080.00	24,472.00	24,840.00	27,600.00	32,200.00	34,040.00	36,800.00
5	21,540.00	25,848.00	28,648.20	29,079.00	32,310.00	37,695.00	39,849.00	43,080.00
6	24,680.00	29,616.00	32,824.40	33,318.00	37,020.00	43,190.00	45,658.00	49,360.00
7	27,820.00	33,384.00	37,000.60	37,557.00	41,730.00	48,685.00	51,467.00	55,640.00
8	30,960.00	37,152.00	41,176.80	41,796.00	46,440.00	54,180.00	57,276.00	61,920.00

For family units of more than 8 members, add \$3,140 for each additional member.

How to Apply for Services

1. Visit a local Department of Human Services (DHS) office.
2. Apply by mail. To get an application call the numbers listed below.

Rhode Island Department of Human Services, Center for Child and Family Health

English: 401-462-1300
Spanish: 401-462-1500
TDD: 401-462-3363

RIte Care Health Plan, Member Services

English: 401-462-1300
Spanish: 401-462-1500

Neighborhood Health Plan of Rhode Island

Beth Marootian
Neighborhood Health Plan of RI
401-459-6000 or 800-963-1001

United Healthcare of New England

Sandi Ferretti, United Healthcare of New England
401-737-6900 or 800-587-5187

Coordinated Health Partners, Inc. (Blue CHiP)

Luisa Valencia
Coordinated Health Partners, Inc.
401-459-5504 or 800-564-0888

RIte Share Health Insurance (Premium Assistance Program)

Helps low and middle income families obtain health insurance coverage through their employer by paying all or part of the employee's share of monthly premiums. Under the RIte Share program, individuals who are income eligible for Medical Assistance and are employed by an employer who offers an approved health plan can enroll in their employer's health insurance plan. The RIte Share program will also pay all or part of co-payments associated with the employer's health plan.

Eligibility

- Pregnant women whose annual income is below 250% of the Federal Poverty Level (FPL)
- Children (birth to age 19) whose family's annual income is below 250% of the FPL
- Families with children under age 18 whose income is below 185% of the FPL

How to Apply for Services

1. Visit a local Department of Human Services (DHS) office; See page 21 **or**
2. Apply by mail. To get an application call the numbers listed below.

Rhode Island Department of Human Services

Center for Child and Family Health

600 New London Avenue

Cranston, RI 02920

English: 401-462-1300

Spanish: 401-462-1500

TDD: 401-462-3363

Specific Disorders and Disabilities

In this section we have listed many resources that are available to families about genetic disorders, birth defects, and disabilities. The Internet is a great tool to search for information. If you don't have a computer, all of the libraries in Rhode Island have computers for public use. If you have questions on something we haven't covered please call Family Voices of Rhode Island at 401-727-4144 x162 for assistance.

Allergies and Asthma

Asthma and Allergy Foundation of America
1233 20th Street, N.W., Suite 402
Washington, DC 20036
Phone: 202-466-7643 or 800-727-8462
Fax: 202-466-8940
www.aafa.org

Draw a Breath Program
Hasbro Children's Hospital
593 Eddy Street
Providence, RI 02903
Phone: 401-444-8340
www.drawabreath.com

Attention Deficit/Hyperactivity Disorder

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
8181 Professional Place, Suite 201
Landover, MD 20785
Phone: 301-306-7070 or 800-233-4050 (Voice mail to request information packet)
national@chadd.org
www.chadd.org

National Attention Deficit Disorder Association (ADDA)
PO Box 1303
Northbrook, IL 60065-1303
mail@add.org
www.add.org

Autism/Asperger's Syndrome

Autism Network International (ANI)
ANI was founded by people with autism for people with autism. There is a membership fee of \$15 per year.
PO Box 35448
Syracuse, NY 13235-5448
ani.autistics.sorg

Autism Society of America (ASA)
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
Phone: 301-657-0881 or 800-3-AUTISM
Fax: 800-FAX-0899
www.autism-society.org

Autism Research Institute (ARI)
ARI publishes the Autism Research Review International. This quarterly review is available for \$18 per year.
4182 Adams Avenue
San Diego, CA 92116
Phone: 619-281-7165
Fax: 619-563-6840
www.autism.com/ari

Autism Society of Rhode Island (ASRI)
ASRI hosts monthly meetings from September through June. ASRI also provides conferences, speakers, a resource center, and a newsletter.
Gateway Plaza, Suite 204
1645 Warwick Avenue
Warwick, RI 02889

Online Asperger Syndrome Information and Support (OASIS)
www.udel.edu/bkirby/asperger/frame2.html

Brain Injury

Brain Injury Association of RI
Independent Square
935 Park Avenue Suite 8
Cranston, RI 02910-2743
Phone: 401-461-6599
BuckleUp1@aol.com
www.biausa.org

Health-Helper
Brain injury, concussion and health resources
www.health-helper.com

BrainTalk Communities
Online patient support groups for neurology
neuro-mancer.mgh.harvard.edu/cgi-bin/Ultimate.cgi

Cancer

American Cancer Society
1599 Clifton Road NE
Atlanta, GA 30329-4251
Phone: 404-320-3333 or 800-227-2345
www.cancer.org

Cerebral Palsy

United Cerebral Palsy of RI (UCP)
Christiane Petrin Lambert, Executive Director
200 Main Street, Suite 210
PO. Box 36
Pawtucket, RI 02862
Phone: 401-728-1800
Fax: 401-728-0182
www.ucpri.org

Deaf-Blind

National Family Association for Deaf-Blind
111 Middle Neck Road
Sandy Point, NY 11050-1129
Phone: 800-255-0411 x 275
TTY: 516-944-8637
Fax: 516-944-7302
www.helenkeller.org.national

Developmental Disabilities

Blackstone Valley Chapter RIARC

The Blackstone Valley Chapter provides services and support to persons with mental retardation and their families. The Center assists individuals in making decisions and taking responsibility for their lives, and helps the community learn about the abilities and potential of citizens with mental retardation. Program services include:

- Living (residential) support
- Employment support
- Personal Wellness Support
- Community Inclusion Support
- Vocational Evaluation
- Community Resource Identification and Access
- Educational Services
- Speech and Language Services
- Nursing Services
- Behavioral/Psychosocial Services
- Physical Therapy Services
- Nutritional and related health services
- Community Recreational Services and Supports

Peter Holden, Executive Director
115 Manton Street
Pawtucket, RI 02861
Phone: 401-727-0150
Fax: 401-727-0153
Email: contact@bvcriarc.org
www.bvcriarc.org

Cranston Arc

The mission of Cranston Arc (formerly the Cranston Center) is to empower people with differing abilities to claim and enjoy their rights to dignity and respect. The Arc believes everyone has abilities and can be a participating member of society. Cranston Arc provides social, recreational, and vocational services for children and adults with developmental disabilities including day programs, residential programs, respite programs, and recreational activities.

Thomas Kane, Executive Director

905 Pontiac Avenue

Cranston, RI 02920

Phone: 401-941-1112 or 401-942-3445

www.cranstonarc.org

RI Arc

James Healey, Executive Director

99 Bald Hill Road

Cranston, RI 02920

Phone: 401-463-9191

Fax: 401-463-9244

Riarc@compuserve.com

The Arc of the US

www.TheArc.org

Diabetes

American Diabetes Association - National Service Center

1660 Duke Street

Alexandria, VA 22314

Phone: 703-549-1500 or 800-342-2383

Fax: 703-549-6995

www.diabetes.org

Down Syndrome

Down Syndrome Society of RI

Claudia M. Lowe

99 Bald Hill Road

Cranston, RI 02920

Phone: 401-463-5751

www.dssri.org

coordinator@dssri.org

Epilepsy

American Epilepsy Society

638 Prospect Avenue

Hartford, CT, 06105-4240

Phone: 860-586-7505

Fax: 860-586-7550

www.aesnet.org

Epilepsy Foundation of America

4351 Garden City Drive

Landover, MD 20785-2267

Phone: 301-459-3700 or 800-332-

4050

Fax: 301-577-2684

www.efa.org

Epilepsy Foundation of Massachusetts and Rhode Island

Joanne LaFortaine, William Murphy

Executive Directors

95 Berkeley Street, Suite 409

Boston, MA 02116

Phone: 617-542-2292 or 888-576-9996

ne-index.shriver.org/Factsweb/

2206.htm

Genetic Disorders

Alliance of Genetic Support Groups
4301 Connecticut Avenue
Washington, DC 20008-2304
Phone: 202-966-5557 or 800-336-GENE
Fax: 202-966-8553
www.geneticalliance.org

National Organization for Rare Disorders (NORD)
100 Rt. 37
PO Box 8923
New Fairfield, CT 06812-8923
Phone: 203-746-6518 or 800-999-6673
www.rarediseases.org

MUMS: National Parent to Parent Network
Julie J. Gordon
150 Custer Court
Green Bay, Wisconsin 54301-1243
Phone: 920-336-5333 or 877-336-5333 (Parents only please)
Fax: 920-339-0995
mums@netnet.net
www.netnet.net/mums

Hearing Impairment

National Association of the Deaf (NAD)
814 Thayer Avenue
Silver Spring, MD 20910-4500
Phone: 301-587-1788
TTY: 301-587-1789
Fax: 301-587-1791
www.nad.org

Alexander Graham Bell Association for the Deaf and Hard of Hearing
3417 Volta Place, N.W.
Washington, DC 20007-2778
Phone and TTY: 202-337-5220
Fax: 202-337-8314
www.agbell.org

American Society for Deaf Children
P.O. Box 3355
Gettysburg, PA 17325
Phone and TTY: 717-334-7922
Fax: 717-334-8808
www.deafchildren.org

First Connections - Training Resource Project for Newborn Screening
Mary Jane Johnson
One Corliss Park
Providence, RI 02908
Phone: 401-222-4013
Fax: 401-222-6998

Relay RI
Provides for communications between individuals using TTY devices and persons using regular telephones.
Phone: 800-745-6575 or 711 for easy access
TTY: 800-745-5555
Spanish Phone: 800-855-2885
Spanish TTY: 800-855-2884
AT&T Operator for the Deaf (OSD): 800-855-1155
Relay Consumer Service Number: 800-682-8706 Voice; 800-682-8786 TTY

Rhode Island Association of the Deaf (RIAD)
Provides support and active advocacy for Deaf and Hard of Hearing citizens of Rhode Island. RIAD is an affiliated member of the National Association of the Deaf (NAD), one of the oldest and largest consumer organizations for disabled persons in the US.
Maria G. Okwara, President
PO Box 40853
Providence, RI 02940
TDD: 401-431-0465
Relay: 800-745-6575
EarnestO@aol.com
members.aol.com/Earnesto/RIAD.html

RI Commission on the Deaf and Hard of Hearing
One Capitol Hill, Ground Floor
Providence, RI 02906
TTY: 401-222-1205
Fax: 401-222-5736
slane@doa.state.ri.us

RI DeafWorldWeb
www.deafworldweb.org/int/us/ri

RI Speech-Language-Hearing Association
Eve Evans Sadd, President
PO Box 9241
Providence, RI 02940
Phone: 401-438-9500
sadd@uri.edu
professional.asha.org/states/rhodeisland.htm

Self Help for the Hard of Hearing (SHHH): RI Chapter
Sargent Rehabilitation Center
2nd Floor Conference Room
229 Waterman St.
Providence, RI 02905
Phone: 401-751-3113
shhhsargents@usa.com
www.shhhsargents.homestead.com/index.html

Heart Disorders

American Heart Association

7272 Greenville Avenue

Dallas, TX 75231-4596

Phone: 214-706-1176 or 800-242-8721

Fax: 214-706-2139

www.amhrt.org

HIV/AIDS

HIV/AIDS in Rhode Island (including anonymous & confidential testing sites)

www.doh.state.ri.us/disprev/communicable/hiv_aids.htm

AIDS Care Ocean State

18 Parkis Avenue

Providence, RI 02907

Phone: 401-521-3603

Fax: 401-861-2981

aidscares.org

AIDS Project RI

232 West Exchange Street

Providence, RI 02906

Hotline: 800-726-3010

Phone: 401-831-5522

TDD: 401-831-5693

Fax: 401-454-0299

www.aidsprojectri.org

aprihotline@hotmail.com

National Pediatric and Family HIV Resource Center

30 Bergen Street, ADMC-4

Newark, NJ 07107

Phone: 973-972-0410 or 800-362-0071

Fax: 973-972-0399

www.wdcnet.com/pedsaids

Learning Disabilities

Literacy Volunteers of America/RI

Donna Sherman

260 West Exchange Street, Suite 106

Providence, RI 02903

Phone: 401-861-0815

National Adult Literacy & Learning Disabilities Center (NALLD)

Academy for Educational Development

1875 Connecticut Avenue, NW

Washington, DC 20009-1202

Phone: 202-884-8185 or 800-953-ALLD (800-953-2553)

Fax: 202-884-8429

www.ld-read.org

Mental/Behavioral Health (For information, see page 36)

Multiple Sclerosis

National Multiple Sclerosis Society, RI Chapter
Gwen Norwood Reeve, Program Director
205 Hallene Road
Warwick, RI 02886
Phone: 401-738-8383
www.nmssri.org

Rare Disorders and Diseases

Search and Respond
c/o Exceptional Parent Magazine
555 Kinderkamack Road
Oradell, NJ 07649-1517
Phone: 202-634-6550
Fax: 202-634-6570
www.eparent.com

National Organization for Rare Disorders (NORD)
100 Route 37
PO Box 8923
New Fairfield, CT 06812-8923
Phone: 203-746-6518 or 800-999-6673
www.rarediseases.org

Speech Disorders

RI Speech-Language-Hearing Association
Eve Evans Sadd, President
PO Box 9241
Providence, RI 02940
Phone: 401-438-9500
sadd@uri.edu
professional.asha.org/states/rhodeisland.htm

Spina Bifida

Spina Bifida Association of RI
Deborah Gellman, President
PO Box 6948
Warwick, RI 02887
Phone: 401-732-7862
DAHLIADEBZ@aol.com
www.sbaa.org

Transverse Myelitis

Transverse Myelitis Information
www.myelitis.org

Visual Impairments

American Foundation for the Blind
Regine Genwright, Director of Information Center
11 Penn Plaza, Suite 300
New York, NY 10001
Phone: 212-502-7600 or 800-726-3010
TTY: 212-502-7662
afbinfo@afb.org
www.afb.org

IN-SIGHT Programs in Productive Living for the Blind
A private, non-profit organization incorporated in 1925 to serve the needs of Rhode Island's blind and visually-impaired population of all ages. IN-SIGHT gives people the opportunity to lead more mobile, independent, and productive lives.
Judith Smith, President
43 Jefferson Boulevard
Warwick, RI 02888
Phone: 401-941-3322

IN-SIGHT Radio

A non-profit, non-commercial, closed circuit radio reading service for the blind and print-handicapped of Rhode Island and surrounding areas. IN-SIGHT RADIO provides current printed material (newspapers, magazines, books) to listeners who are unable to use printed materials due to a visual or a physical disability. Half of each broadcast day consists of readings taken from national, state and local newspapers. Emphasis is given to features that are unique to a newspaper such as food advertisements, editorials, death notices, and columns. IN-SIGHT RADIO also offers a variety of special interest programs focusing on consumerism, health, retirement concerns, and entertainment listings. In addition, the programs are delivered to homes through four cable television systems. To be eligible for IN-SIGHT RADIO a person must have a visual or physical handicap that prevents him or her from reading conventional printed material.

43 Jefferson Boulevard
Warwick, RI 02888
Phone: 401-941-3322

National Library Service for the Blind and Physically Handicapped
lcweb.loc.gov/nls/nls.html

OSCIL Sign Language Interpreter Referral Service

Requests for an interpreter should be made at least two weeks in advance. Be sure to leave the following information with the referral service: agency name, address, telephone number and contact person; date interpreter is needed; location, time and length, and nature of event for which the interpreter is needed; type of sign language interpreter preferred by consumer (ASL, Signed English, Oral).

Phone: 800-525-0770
TDD: 800-232-0438
www.oscil.org

Services for the Blind and Visually Impaired (SBVI)

The purpose of Services for the Blind and Visually Impaired is to provide eligible individuals with visual impairments the opportunities and support that will enable them to become independent, active, self-sustaining members of their communities.

Office of Rehabilitation Services
40 Fountain Street
Providence, RI 02903
Phone: 401-222-2300 or 800-752-8088 x2300
TDD: 401-222-3010
Cambodian: 401-272-7990
Spanish: 401-272-8090
Fax: 401-222-1328
www.ors.state.ri.us/sbvipage.htm

Talking Books Plus: RI Regional Library for the Blind and Physically Handicapped

The Regional Library serves as a public library for eligible persons residing in Rhode Island by loaning special reading materials and equipment free of charge. Books recorded on cassettes as well as large print and Braille books are mailed postage free to individuals qualifying for this service. Special cassette and talking book machines specifically designed for use with the recorded materials are issued along with the materials. All of the services mentioned are available to persons of any age who qualify on the basis of a visual or physical handicap that prevents them from using conventional print materials, and who can provide certification by a competent authority. Regional Libraries are located in all states in the United States. The National Library Service for the Blind and Physically Handicapped (NLS), a program sponsored by the Library of Congress, provides all talking books and the equipment on which they are played.

Andrew Egan, Supervisor
Office of Library and Information Services
One Capitol Hill
Providence, RI 02908
Phone: 401-222-5800 or 800-734-5141 (in-state)
tbplus@lori.state.ri.us
www.lori.state.ri.us/TBP/default.htm

Vision Services Program

The Vision Services Program provides services to children who are blind or visually impaired.

Contact

Claire Irwin

Vision Services Program

1 Corliss Park

Providence, RI 02908

Phone: 401-222-3827

Rhode Island Services for Children and Youth with Dual Sensory Impairment

This federally funded project provides training and technical assistance related services to children and youth with dual sensory impairments (vision and hearing impairments). Dual sensory impairments means having both auditory and visual impairments that create such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services.

Dr. Susan Dell, Project Coordinator

Rhode Island Services for Children and Youth with Dual Sensory Impairment

Sherlock Center on Disabilities

Rhode Island College

600 Mount Pleasant Avenue

Providence, RI 02908

Phone: 401-456-8072

Fax: 401-456-8150

Hospitals

Hasbro Children's Hospital

593 Eddy Street

Providence, RI

Phone: 401-444-4000

Boston Children's Hospital

300 Longwood Avenue

Boston, MA 02115

Phone: 617-732-5500

Providence Ronald McDonald House

Provides a home-away-from-home for families of children receiving treatment at local hospitals, primarily Women & Infants, Hasbro Children's and Bradley Hospitals. Families of pregnant women in need of prolonged hospitalization and families of premature infants also are welcome at the House.

45 Gay Street

Providence, RI 02905

Phone: 401-274-4447

Fax: 401-751-3730

prmh@tiac.net

www.rmhc.com

Psychiatric Hospitals

Arbour-Fuller Hospital

200 May Street

South Attleboro, MA

Phone: 401-761-8500

www.arbourhealth.com

Bradley Hospital

A psychiatric center for children, adolescents, and their families. Also provides in-home services.

1011 Veterans Memorial Parkway

East Providence, RI 02915

Phone: 401-432-1000

Butler Hospital

345 Blackstone Boulevard

Providence, RI 02906

Phone: 401-455-6200

Shriner's Hospitals

Boston Shriner's Hospital, Burn Center

51 Blossom Street

Boston, MA 02114

Phone: 617-722-3000

Springfield Shriner's Hospital, Orthopedic

516 Carew Street

Springfield, MA

Phone: 413-787-2000

www.shrinershq.org

Therapy Services

This includes resources for Occupational, Physical, Speech, Social Skills and Therapeutic Recreation.

Rehab New England

Rehab New England provides occupational and physical therapy, and speech pathology services to children birth-21 years old. In-home services are provided as well.

120 Lambert Street
Warwick, RI 02886
Phone: 401-739-5900

Meeting Street Center

667 Waterman Avenue
East Providence, RI 02914
Phone: 401-438-9500

AOTA- American Occupational Therapy Association

4720 Montgomery Lane
PO Box 31220
Bethesda, MD 20824-1220
Phone: 301-652-2682
www.aota.org

RI Occupational Therapy Association

PO Box 40203
Providence, RI 02940-0203
Phone: 401-726-8473

American Physical Therapy Association

www.apta.org

RI American Physical Therapy Association

Phone: 401-874-5391

RI Speech-Language-Hearing Association

Eve Evans Sadd, President
PO Box 9241
Providence, RI 02940
Phone: 401-438-9500
sadd@uri.edu
professional.asha.org/states/rhodeisland.htm

Therapeutic Recreation

Boys and Girls Clubs of Providence

33 Atwood Street
PO Box 3270-09
Providence, RI 02909
Phone: 401-444-0750
Fax: 401-444-0757

Boy Scouts of America

Narragansett Council
175 Broad Street
Providence, RI 02903-4081
Phone: 401-351-8700
www.narragansettbsa.org

Disabled Sports USA

451 Hungerford Drive, Suite 100
Rockville, MD 20850
Phone: 301-217-0960
Fax: 301-217-0968
www.dsusa.org

Girl Scouts of RI

125 Charles Street
Providence, RI 02904
Phone: 401-331-4500
www.gsusa.org

Greenlock Therapeutic Riding Center

55 Summer Street
Rehoboth, MA 02769
Phone: 508-252-5814

Groden Center

86 Mount Hope Avenue
Providence, RI 02906
Phone: 401-274-6310

Impossible Dream Park

575 Centerville Road
Warwick, RI 02886
Phone: 401-823-5566

John Hope Settlement House

7 Burgess Street
Providence, RI 02903
Phone: 401-421-6993

Piano and Voice Lessons

Kathy Field, B.S. Music Education
Experience teaching children with autism.
Phone: 401-333-9656

RI Family Guide- Summer Camp Directory

PO Box 163
Warren, RI 02885
Phone: 401-247-0850
www.rifamilyguide.com

Shake A Leg

Provides mainstream, complimentary, and recreational therapeutic services (including 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
Voice: 401-849-8898
Fax: 401-848-9072
www.shakealeg.org

Special Olympics RI

33 College Hill Road
Warwick, RI 02886
Phone: 401-823-7411
Fax: 401-823-7415
www.specialolympics.org

Tides Family Services

1599 Main Street
West Warwick, RI
Phone: 401-831-1360

Tri-State Multi Services

7 Country View Drive
Coventry, RI
Phone: 401-828-6210

Very Special Arts RI

Jeannine Chartier, Executive Director
500 Prospect Street
Pawtucket, RI 02860
Phone: 401-725-0247
TTY: 800-745-5555 (TTY)
ride0057@ride.ri.net
www.vsarts.org/affiliates/states/ri.lasso

Mental/Behavioral Health

Alliance for the Mentally Ill of RI
1255 North Main Street
Providence, RI 02904
Phone: 401-331-3060
nicknami@aol.com
ri.nami.org

**Department of Mental Health,
Retardation & Hospitals (MHRH)**
A. Kathryn Power, Director
14 Harrington Road
Cranston, RI 02920
Phone: 401-462-3201
TDD: 401-462-6087
Fax: 401-462-3204
kpower@mhrh.state.ri.us
www.mhrh.state.ri.us

**Manic Depressive and Depressive
Association of RI**
53 Lafayette Drive
Bristol, RI 02809
Phone: 401-254-2572

**Mental Health Advancement
Resource Center (MHARC)**
500 Prospect Street
Pawtucket, RI 02860
Phone: 401-726-8383
RI Relay: 800-745-6575
Fax: 401-726-2287
MHARC@conversent.net
www.mharc.com

Mental Health Association of RI
Cynthia A. O'Neil, Executive Director
500 Prospect St.
Pawtucket, RI 02860
Phone: 401-726-2285
mmhari@aol.com

Parent Support Network
400 Warwick Ave
Warwick, RI 02886
Phone: 401-467-6855 or 800-483-8844

**Providence Community Action
(ProCap)**
662 Hartford Avenue
Providence, RI 02909
Phone: 401-272-0660

**RI Council of Community Mental
Health Centers**
67 Cedar Street, Suite 1
Providence, RI 02903
Phone: 401-273-0900

Web Resources

*CMHS' Knowledge Exchange Association
(Center for Mental Health Services)*
www.mentalhealth.org

*Mental Health Advancement Resource
Center (MHARC)*
www.mharc.com/home.htm

*National Alliance for the Mentally Ill,
NAMI RI*
ri.nami.org

*National Association of State Alcohol and
Drug Abuse Directors (NASADAD)*
www.nasadad.org

*National Association of State and Mental
Health Program Directors*
www.nasmhpd.org

*National Clearinghouse for Alcohol and
Drug Information*
www.health.org

National Consumer Empowerment Center
www.power2u.org

*National Institute of Mental Health
(NIMH)*
www.nimh.nih.gov

*National Technical Assistance Center
(NTACT)*
www.nasmhpd.org/nt

Substance Abuse Resources

CMHS' Knowledge Exchange Association
www.mentalhealth.org

HIV/AIDS in RI
www.doh.state.ri.us/disprev/commu-
nicable/hiv_aids.htm

Manisses Communications Group
Information in the behavioral health field
www.bhrpress.com/free_reports.htm

*Mental Health Advancement Resource
Center (MHARC)*
www.mharc.com/home.htm

*National Alliance for the Mentally Ill,
NAMI RI*
www.nami.org/about/amiri

*National Association of State Alcohol and
Drug Abuse Directors*
www.nasadad.org

*National Association of State and Mental
Health Program Directors (NASMHPD)*
www.nasmhpd.org

*National Clearinghouse for Alcohol and
Drug Information*
www.health.org

*National Institute of Mental Health
(NIMH)*
www.nimh.nih.gov

*Rhode Island Council on Alcoholism and
Other Drug Dependence Helpline*
Phone: 401-725-0410 or 800-622-7422

*Substance-Abuse Related Communicable
Diseases*
www.doh.state.ri.us/disprev/commu-
nicable/commhome.htm

Children's Intensive Services

Community Counseling Center
160 Beechwood Avenue
Pawtucket, RI 02860
Phone: 401-722-5573

East Bay Mental Health Center
2 Old Country Road
Barrington, RI
Phone: 401-246-1195

Kent County Mental Health Center
300 Centerville Road, Suite 301-5
Warwick, RI 02886
Phone: 401-732-5656

*Mental Health Services of Cranston,
Johnston, and Northwestern RI*
1443 Hartford Avenue
Johnston, RI 02919
Phone: 401-273-8100 or 888-841-5252

*Newport County Community Mental
Health Center*
127 Johnny Cake Hill
Middletown, RI 02842
Phone: 401-846-1213

*Northern RI Community Mental Health
Center*
Serving: Woonsocket, N. Smithfield,
Burrrville, Cumberland, Lincoln
55 Cummings Way
Woonsocket, RI 02895
Phone: 401-766-3330

The Providence Center
520 Hope Street
Providence, RI 02906
Phone: 401-276-4000

*South Shore Community Mental Health
Center*
4705A Old Post Road, 1A South
Charleston, RI 02813
Phone: 401-364-7705

Children's Emergency Services

*Child and Family Services of Newport
County*
24 School Street
Newport, RI
Phone: 401-841-8840

Community Counseling Center
160 Beechwood Avenue
Pawtucket, RI
Phone: 401-722-5573

Cranston Community Action Program
41 Heath Avenue
Cranston, RI
Phone: 401-467-9610

Family Services, Inc.
55 Hope Street
Providence, RI 02906
Phone: 401-331-1350

John Hope Settlement House
7 Burgess Street
Providence, RI 02903
Phone: 401-421-6993

Kent County Mental Health Center
300 Centerville Road, Suite 301-5
Warwick, RI 02886
Phone: 401-738-4300

*Mental Health Services of Cranston,
Johnston, and Northwestern RI*
1443 Hartford Avenue
Johnston, RI 02919
Phone: 401-273-8100 or 888-841-5252

Rhode Island Youth Guidance Center
82 Pond Street
Pawtucket, RI 02860
Phone: 401-725-0450

*South Shore Community Mental Health
Center*
4705A Old Post Road, 1A South
Charleston, RI 02813
Phone: 401-364-7705

Family Resources Community Action
245 Main Street
Woonsocket, RI 02895
Phone: 401-766-0900

Community Mental Health Centers in Rhode Island

RI Council of Community Mental Health Centers

A Community Mental Health Center in each area serves as single point of entry for services and provides:

- 24-Hour Emergency Service
 - Inpatient Services
 - Psychiatric Services
 - Medication Maintenance
 - Community Residences
 - Psychiatric Rehab, including employment
 - CPST, including help finding work and housing
 - Counseling Services
- 67 Cedar Street, Suite 1
Providence, RI 02903
Phone: 401- 273-0900
Fax: 401-273-0901

Community Counseling Center, Inc.

160 Beechwood Avenue
Pawtucket, RI 02860
Phone: 401-722-5573
Intake: 401-723-1915

East Bay Mental Health Center, Inc.

2 Old County Road
Barrington, RI 02806
Phone: 401-246-1195
Intake: 401-431-9870

Kent County Mental Health Center, Inc.

50 Health Lane
Warwick, RI 02886
Phone: 401-738-4300
Intake: 401-738-4300

Mental Health Services of Cranston, Johnston and Northwestern RI, Inc.

516 Atwood Avenue
Johnston, RI 02919
Phone: 401-273-8100
Intake: 401-273-8100

Newport County Community Mental Health Center, Inc.

127 Johnnycake Hill Road
Middletown, RI 02842
Phone: 401-846-1213
Intake: 401-846-1213

Northern R.I. Community Mental Health Center, Inc.

515 Social Street
P.O. Box 1700
Woonsocket, RI 02895
Phone: 401-766-3330
Intake: 401-762-1577

The Providence Center for Counseling and Psychiatric Services

520 Hope Street
Providence, RI 02906
Phone: 401-276-4000
Intake: 401-276-4020

South Shore Mental Health Center, Inc.

4705A Old Post Road
P.O. Box 899
Charlestown, RI 02813
Phone: 401-364-7705
Intake: 401-364-7705

CASSP and the Local Coordinating Council

"CASSP" stands for Child and Adolescent Service System Program, a system of care for children and youth with severe emotional disturbances. Each of eight mental health catchment areas in the state has a Local Coordinating Council, or LCC, to serve their community. The LCC is made up of representatives from mental health, social service, and recreation agencies, local education authorities, state agencies involved with child and family issues, parent advocates, and most importantly parents.

The LCC is charged with pulling together a continuum of services that meet the needs of children with serious emotional or behavioral challenges and their families in a culturally competent, community-based, child centered and family focused way. The LCCs are responsible for ensuring that services are accessible to families and, most importantly, that families are integral partners in determining the best service plans for their children.

This is accomplished through the use of planning teams composed of formal and informal supports identified by the family, family members, and a Family Service Coordinator from the LCC. The latter is an individual with experience in negotiating various service systems within the state. The Family Service Coordinator assists the family in identifying their strengths, needs, and service requests that are then brought to the planning team for the development of an individual service plan for the child and family.

Eligibility

Children and Youth eligible for CASSP are:

- between the ages of birth and twenty-one (21) years;
- have a serious emotional, behavioral, or mental disorder (DSM-IV) with the exception of ("V" codes) substance abuse and developmental disorders, unless they are a co-occurring disorder with another serious emotional disturbance;
- have a disability that has been, or is potentially on-going for a period of one (1) year or more;
- are in need of multi-agency intervention; and
- are at risk for out of home or more restrictive placements due to emotional/behavioral problems.

Note: A similar program, Project Hope, exists for adjudicated youth exiting the RI Training School. Information can be obtained on project Hope by contacting any of the LCC/CASSP sites listed below.

CASSP/LCC Contacts

Providence

John Hope Settlement House
7 Burgess Street
Providence, RI 02903
Phone: 401-421-6993
Fax: 401-454-5619

Northern Rhode Island

(Woonsocket, Cumberland, Lincoln,
North Smithfield, Burrillville)
Stadium Building
1 Social Street
Woonsocket, RI 02895

Pawtucket / Central Falls

Community Counseling Center
160 Beechwood Avenue
Pawtucket, RI 02860
Phone: 401-722-5573 x232
Fax: 401-726-5571

Kent County

(Warwick, West Warwick, Coventry,
West Greenwich, East Greenwich)
Kent County Mental Health Center
Summit South
300 Centerville Road, Suite 301S
Warwick, RI 02886
Phone: 401-732-5656
Fax: 401-738-8634

Metro West

(Cranston, Foster, Glocester, Johnston,
Scituate, Smithfield)
Mental Health Services of Cranston,
Johnston, and NWRI
311 Doric Avenue
Cranston, RI 02910
Phone: 401-784-3633
Fax: 401-784-3636

Washington County

(Charlestown, Exeter, Hopkinton,
Narragansett, North Kingstown, South
Kingstown, Richmond, Westerly, New
Shoreham)
South Shore Community Mental
Health Center
730 Kingstown Road
Wakefield, RI 02879
Phone: 401-789-1166
Fax: 401-789-7035

Newport

(Jamestown, Little Compton,
Middletown, Portsmouth, Tiverton)
CASSP Staff Supervisor
401-848-6363

Family Education, Advocacy, and Support

Family education, advocacy, and support programs provide informational and emotional support to families who have a child, adolescent, or adult family member with special needs. They offer an important connection for a family who is seeking support for a specific disability issue, through group discussion in support groups and in meeting other families who are further along in their journey. We have also included a section on *family fun*.

The Rhode Island Parent Information Network

The Rhode Island Parent Information Network (RIPIN), which houses Family Voices of RI, is a statewide, non-profit organization committed to empowering, educating and encouraging families to seek positive outcomes for their children.

Families and professionals seek the expertise and guidance of RIPIN staff via telephone, email, in person, or by participating in one of many training workshops. Training and parenting information focuses on education, child development, disabilities, health care, effective home-school partnerships, fatherhood, Early Intervention, transition planning, violence prevention, literacy, basic rights, special education law and more. In addition to offering families with children guidance, referrals, training and support, RIPIN maintains a lending library of books and videos and a website full of helpful links and resources for helping all children reach their full potential.

175 Main Street

Pawtucket, RI 02860

Phone: 401-727-4144 or 800-464-3399 (toll free in RI only)

Fax: 401-727-4040

ripin@ripin.org

www.ripin.org

Parent Support Network of Rhode Island (PSN)

This program is a statewide organization of families supporting families that have children who are at risk or have behavioral and/or emotional challenges. Support is provided that considers a family's background and values. The Parent Support Network (PSN) provides support groups, telephone support, educational events, one-to-one assistance with advocacy and literature about education, mental health, and parenting a child with special emotional or behavioral needs.

400 Warwick Avenue

Warwick, RI 02886

Phone: 401-467-6855 or 800-483-8844

Adoption Rhode Island

500 Prospect Street

Pawtucket, RI 02860

Phone: 401-724-1910

adoptionri.org

Amputee Peer Support Group

Sponsored by OSCIL

Susan Eleoff

Phone: 401-738-1013

TDD: 401-738-1015

Bipolar/Mental Health Support Group

For families of children with mental health concerns.

Meetings held on the first and third Tuesday of every month.

Childcare is available if registered early.

Chris Brown at 401-432-1205

Linda Remarski at 401-658-2552

Cheryl Santos at 401-941-1891

Bradley Hospital

1011 Veterans Memorial Parkway

East Providence, RI

Bradley Hospital

1011 Veterans Memorial Parkway

East Providence, RI

Phone: 401-434-3400

Brain Injury Association of RI

Support groups for head injury survivors and their families.

Michelle Branch

Phone: 401-725-2360

BrainTalk Communities: Online Patient Support Groups for Neurology

neuro-mancer.mgh.harvard.edu/cgi-bin/Ultimate.cgi

Directory of State Protection and Advocacy Agencies

Trace Center @ College of Engineering, University of Wisconsin - Madison

trace.wisc.edu/docs/quick_sheets

Exceptional Parent

www.eparent.com

Family Village

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 services and support.
www.familyvillage.wisc.edu

Groden Center

88 Mount Hope Avenue
Providence, RI 02906
Phone: 401-274-6310

Multiple Sclerosis Support and Outreach Groups

Sponsored by National Multiple Sclerosis Society, RI Chapter.
Gwen Norwood Reeve
Phone: 401-738-8383

National Information Center for Children and Youth with Disabilities

PO Box 1492
Washington, DC 20013-1492
Phone/TTY: 202-884-8400 or 800-695-0285
Fax: 202-884-8441
nichey@aed.org
www.nichcy.org

Online Asperger Syndrome Information and Support (OASIS)

www.udel.edu/bkirby/asperger

OSCIL Drop-In Center

Social and recreational group for ages 13 to 30. Registration required. Meetings are monthly.
Ann Marie Breslin
Phone: 401-738-1013
TDD: 401-438-1015
www.oscil.org

Parent Information Center (Northeast Regional Center)

PO Box 2405
Concord, NH 03302-2405
Phone: 603-224-7005
Fax: 603-224-4379
picnh@aol.com

Parent Teacher Association (PTA)

RIC Campus-Building #6
600 Mt. Pleasant Avenue
Providence, RI 02908
Phone: 401-272-6405

Parents Exchange of Jewish Family Service

229 Waterman Street
Providence, RI 02906
Phone: 401-331-KIDS

Rehabilitation Hospital of RI

Support group for those coping with head injuries.
Contact
Michelle Branch
Phone: 401-766-0800 x5513

Rhode Island Parents' Paper

www.parenthoodweb.com

RI ARC

99 Bald Hill Road
Cranston, RI 02920
Phone: 401-463-9191

Sargent Center

Sargent Rehabilitation Center
800 Quaker Lane
Warwick, RI
Phone: 401-783-9661

Self-Help for Hard of Hearing People (SHHH)

Myron Waldman
Sargent Rehabilitation Center
800 Quaker Lane
Warwick, RI
Phone: 401-783-9661

Sibling Support Group

Sponsored by AMI CAN of RI, Bradley Hospital, and the Mental Health Association of RI
Phone: 401-331-3060

Support Group for Parents of Children with Neuromuscular Diseases

Sponsored by Muscular Dystrophy Association. Meetings held monthly at Rhode Island Hospital.
Mary Leeman
Phone: 401-823-5260

Support Group for People with Seizure Disorders

Janet Mullen
Phone: 401-725-1966

United Way Helpline (Travelers Aid)

177 Union Street
Providence, RI
Phone: 401-351-6500

Young Stroke Support Group

Meetings held on first Wednesday of every month.
Janice B. Hulme
1160 Post Road
Warwick, RI
Phone: 401-781-4441

Legal Assistance/Protection, Information, and Advocacy Agencies

Administration on Developmental Disabilities (ADD)

Administration for Children and Families, U.S. Department of Health and Human Services

The Administration on Developmental Disabilities (ADD) is the federal agency that administers the four programs authorized by the Developmental Disabilities Act. These programs include the Developmental Disabilities Council's Protection and Advocacy Systems, University Affiliated Programs, and Projects of National Significance.

370 L'Enfant Promenade, SW

Mail Stop: HHH F

Washington, DC 20201

Phone: 202-690-6590

www.acf.dhhs.gov/programs/add

add@acf.dhhs.gov

Advocates in Action (statewide self-advocacy group)

Deb Griffin-Kney and Kevin McHale

PO Box 41528

Providence, RI 02940-1528

Phone: 401-785-2028

TDD: 800-745-5555

www.aina-ri.org

Commission for Human Rights

The objective of the Commission for Human Rights is to enforce anti-discrimination laws mandated by state and federal law.

John Susa, Chair

10 Abbot Park Place

Providence, RI 02903

Phone: 401-222-2661

Fax: 401-22-2616

TDD: 401-222-2664

Disability Rights Activist

www.disrights.org

Justice For All

www.jfanow.org

National Association of Protection and Advocacy Systems (NAPAS)

NAPAS represents federally mandated programs that protect the rights of persons with disabilities.

900 2nd Street, NE, Suite 211

Washington, DC 20002

Phone: 202-408-9514

Fax: 202-408-9520

NAPAS@earthlink.net

www.protectionandadvocacy.com

Rhode Island Disability Law Center, Inc.

RIDLc is a non-profit organization that provides free legal assistance to persons with disabilities and distributes information on the rights of people with disabilities.

Raymond L. Bandusky, Executive Director

349 Eddy Street

Providence, RI 02903

Phone: 401-831-3150 or 800-692-7443

TDD: 401-831-5335

Fax: 401-274-5568

www.ridlc.org

Housing

Rhode Island Housing and Mortgage Finance Company

As the state's principal housing agency, we help low- and moderate-income Rhode Islanders find houses and apartments they can afford. Get a low-interest loan to buy a house. Find an apartment you can afford. Get money to repair your home or remove hazardous material such as lead paint and asbestos. We even help developers build affordable apartments. Our mission is to assist Rhode Islanders who, by reason of income, special need or circumstance, are unable to fairly obtain and sustain a healthy, affordable home. More than just a physical structure, a home includes the people within and the community around. We're a self-supporting agency, which receives no state tax dollars. Since 1973, we have helped 175,000 Rhode Islanders find houses and apartments they can afford.

44 Washington Street
Providence, RI 02903-1721
Phone: 401-757-5566
TDD: 401-427-9799
www.rihousing.com

Housing Resources Commission

The Rhode Island Housing Resources Commission (HRC) was created by legislation in 1998 to be the planning and policy, standards and programs agency for housing issues. The Commission's purpose is to ensure that all Rhode Islanders have access to safe and affordable housing. We are a 27 member Commission, representing a wide range of constituents, from government to providers to advocates.

41 Eddy Street
Providence, RI 02906
Phone: 401-450-1350
Fax: 401-450-1394
www.hrc.state.ri.us

Other Resources for Families

Women, Infants, Children Program (WIC)

This health and nutrition program promotes health and development through good nutrition. The program is for pregnant and breastfeeding women and children up to age 5 who are at nutritional risk. Families may apply to the program if their income is at or below 185 percent of the federal poverty level. Additionally, families who currently receive benefits from Medical Assistance, Katie Beckett, Rte Care, Family Independence Program (FIP), and the Food Stamps Program may also apply for WIC benefits. Immigrant women and children may also be eligible. (Includes individuals with or without documented status).

Rhode Island Department of Health; Women, Infants, Children Program
3 Capitol Hill, Room 302
Providence, RI 02908-5097
Phone: 401-222-4604
Fax: 401-222-1442

WIC Clinics in Rhode Island

Chad Brown Health Center
285A Chad Brown Street
Chad Brown Health Center
285A Chad Brown Street
Providence 02908
401-831-0020

Women and Infants Hospital
2 Dudley Street
Providence 02905-2401
401-274-1122 x2798

Allen Berry Health Center
202 Prairie Avenue
Providence 02907
401-444-0570

Capitol Hill Health Center
40 Candace Street
Providence 02908
401-444-0550

Central Health Center
239 Cranston Street
Providence 02907
401-444-0580

Fox Point Health Center
550 Wickenden Street
Providence 02903
401-444-0530

Olneyville Health Center
100 Curtis Street
Providence 02909
401-444-0540

Blackstone Valley Community Health Center
9 Chestnut Street
Central Falls 02863
401-724-7134

John J. Cunningham Health Center
42 Park Place
Pawtucket 02860
401-722-0082

Thundermist Health Association
191 Social Street, 9th Floor
Woonsocket 02895
401-767-4160

*Thundermist Health Association
(Northwest)*
The Bridgeway
Pascoag, 02859
401-568-7661

Tri-Town Health Center
1126 Hartford Avenue
Johnston 02919
401-351-2750 x132

Family Health Services Center
1090 Cranston Street
Cranston 02920
401-946-4650

Ferris Community Health Center
821 West Shore Road
Warwick 02889
401-737-1150

*Warwick CAP, West Warwick Community
Health Center*
53 Providence Street
West Warwick 02893
401-826-3230

Wood River Health Services
832 Main Street
Hope Valley 02832
401-539-2461

Health Center of South County
One River Street
Wakefield 02879
401-782-0855

Health Center of South County (Bayshore)
North Kingstown 02852
401-782-0855

Newport Community Health Center
19 Broadway
Newport 02840
401-847-7821

James F. Silvia Health Center
1048 Stafford Road
Tiverton, RI 02878
401-625-5197

East Providence Health Center
100 Bullocks Point
East Providence 02915
401-437-1007

East Providence Health Center (Warren)
790 Main Street
Warren 02885
401-437-1007

St. Joseph Health Center
21 Peace Street
Providence 02907
401-456-4045

Florence Gray Center
1 York Street
Newport 02840

Family Resource Counselor Program

This program supports community health centers and hospital clinics to enroll families in preventive health and family support programs including Medicaid/RIte Care, Women, Infants, Children (WIC), Food Stamps and the Family Independence Program (FIP). Counselors help families apply for programs and let them know what they may be eligible for. Families can apply at the following locations:

Bayside Family Health Care
North Kingstown
401-295-9706

Family Health Services
Cranston
401-943-1981

Thundermist Health Associates
Woonsocket
401-767-5444 x3476

Health Center of South County
Wakefield
401-783-0523

Family Health Services
Coventry
401-828-5335

Tri-Town Health Center
Johnston
401-351-2750

Blackstone Valley Community Health Care
Pawtucket
401-722-0081

Hasbro Children's Hospital/RI Hospital
Providence
401-444-4000

Women and Infants Hospital
Providence
401-274-1122 x2778

Memorial Hospital
Pawtucket
401-729-2634

Northwest Health Center
Harmony
401-568-7661 x13

Wood River Health Services
Wood River
401-539-2461

Chad Brown Health Center
Providence
401-274-6339

St. Joseph's Health Services
Providence
401-456-4029

Providence Community Health Centers
(see WIC list for this list)

New Visions for Newport County
Newport
401-847-7821

Self Help/East Bay Family Health Care
East Providence
401-437-5105

Family Fun

This is just a small sampling of what you can do with your family. Check your local community listings for events activities in your area for low cost or free fun.

Canobie Lake Park

PO Box 190
Salem, NH 03079-0190
Phone: 603-893-3506
www.canobie.com

FantasyLand

1300 Fall River Avenue
Seekonk, MA 02771

Six Flags Amusement Parks

www.sixflags.com

Spooky World

All rides are accessible, it received a commendation from the Surgeon General for their accessibility efforts.
100 River Road
Berlin, MA 01503-1647
Phone: 978-838-0200

Family Fun

Monthly magazine loaded with activities for all ages.
www.familyfun.com

Elected Government Officials

Information on state representatives and other elected officials is available on the website of the Secretary of State at www.state.ri.us.

United States House of Representatives

Patrick Kennedy (D-First District)

Washington office:
407 Cannon House Office Building
US House of Representatives
Washington, DC 20515
Phone: 401-225-4911 or 800-392-5772 (in Rhode Island)
Fax: 202-225-3290

Rhode Island office:
249 Roosevelt Avenue, Suite 200
Pawtucket, RI 02860
Phone: 401-729-5600
Fax: 401-729-5608
patrick.kennedy@mail.house.gov
www.house.gov/patrickkennedy/contact.html

James Langevin (D-Second District)

Washington office:
109 Cannon House Office Building
US House of Representatives
Washington, DC 20515
Phone: 202-225-2735

Rhode Island office:
300 Centerville Road, Suite 200
Warwick, RI 02886
Phone: 401-732-9400 or 401-453-5294
Fax: 401-737-2982

United States Senators

Lincoln Chafee (R)

Washington office:
United States Senate
505 Dirksen Building
Washington, DC 20510
Phone: 202-224-2921 or 800-662-5188 (in Rhode Island)
TTY: 202-224-7746
E-mail: senator_chafee.senate.gov
Website: www.senate.gov/~chafee/

Rhode Island office:
170 Westminster Street, Suite 1100
Providence, RI 02903
Phone: 401-453-5294

Jack Reed (D)

Washington office:
United States Senate
320 Hart Senate Office Building
Washington, DC 20510-3901
Phone: 202-224-4642
Fax: 202-224-4680
Email: jack@reed.senate.gov
Website: www.senate.gov/~reed

Rhode Island office:
201 Hillside Road, Suite 200
Cranston, RI 02920-5602
Phone: 401-943-3100 or 800-284-4200
TDD: 800-745-5555
Fax: 401-464-6837

Governor

Governor Donald L. Carcieri

222 State House
Providence, RI 02903
Phone: 401-222-2080
rigov@gov.state.ri.us
www.governor.state.ri.us

State Departments, Agencies, and Commissions

Governor's Commission on Disabilities

John O. Pastore Center (formerly the Howard Center)

Executive Secretary: Bob Cooper

41 Cherry Dale Court

Cranston, RI 02920-3049

Phone: 401-462-0100

TTY: 401-462-0101

Fax: 401-462-0106

disabilities@gcd.state.ri.us

www.gcd.state.ri.us

Rhode Island General Assembly

www.rilin.state.ri.us

Rhode Island Office of Rehabilitation Services

www.ors.state.ri.us

Rhode Island Department of Children, Youth, and Families

www.dcyf.state.ri.us

Rhode Island Department of Education

www.ridoe.net

Rhode Island State Department of Health

www.healthri.org

Rhode Island Department of Human Services

Phone: 888-DHS-3322

www.dhs.state.ri.us

Rhode Island Department of Mental Health, Retardation, and Hospitals

www.mhrh.state.ri.us

Rhode Island Government Owner's Manual (free of charge)

401-222-2357

www.state.ri.us/rimanual

Child Care Subsidies, Department of Human Services

Phone: 888-DHS-3322

www.dhs.state.ri.us

Child Support Enforcement Office, Department of Human Services

Phone: 800-638-KIDS

www.dhs.state.ri.us

Electronic Benefit Transfer (EBT)

Customer Service

Department of Human Services

Phone: 888-979-9939

Family Independence Program, Department of Human Services

Phone: 888-DHS-3322

www.dhs.state.ri.us

Food Stamps, Department of Human Services

Phone: 800-662-5018

www.dhs.state.ri.us

Earned Income Tax Credit Information, Internal Revenue Service

Phone: 800-829-1040

Political Information

Congress

congress.org

Federal Election Commission - The National

Mail Voter Registration Form

www.fec.gov/votregis/vr.htm

Project Vote Smart - A Voter's Self-Defense System

www.vote-smart.org

CanDo.com

cando.com

I-CAN Online

www.icanonline.net

WEmedia

www.wemedia.com

Disability Information

*Ability to Independence - The VISUAL
disAbility Expo for the disAbleD*
Website: remote-ability.com

*California State University, Northridge-
Center On Disabilities*
www.csun.edu/cod

*CDC-National Center for Birth Defects and
Developmental Disabilities*
www.cdc.gov/ncbddd

Cornucopia of Disability Information
codi.buffalo.edu

Creativity Explored
www.creativityexplored.org

Dealing with Disability
www.metlife.com/index

Disability News Service
www.disabilitynews.com

Disability News Ticker
www.abilityinfo.com/ticker.html

Films Involving Disabilities
www.disabilityfilms.co.uk

*GARAVENTA (Canada) LTD - Accessibility
Solutions*
www.garaventa.com

*Health-Helper - Brain Injury, Concussion
and Health Resources*
www.health-helper.com

*Integrated Arts-Home for Creative
Expression*
www.icomm.ca/iarts

*Internet Resources for Special Children
(IRSC)*
www.irsc.org

National Institute of Art & Disability
www.niadart.org

*National Library Service for the Blind and
Physically Handicapped*
www.lcweb.loc.gov/nls

*On A Roll - Talk Radio on Life and
Disability*
www.onarollradio.com

*rehabNET - Resource on Disability and
Medical Rehabilitation*
www.rehabnet.com/index.html

Through the Looking Glass
www.lookingglass.org

Trace Research and Development Center
www.trace.wisc.edu

Feedback Form

We would like to know your thoughts about this guide, and suggestions you may have for inclusion in future updates. Please use the space below to share your comments or to report corrections. We especially appreciate comments about how you have or will use this information to help your child(ren) and/or yourself. Thank you in advance.

Comments

Corrections

Page: _____

Entry: _____

Correct information: _____

Page: _____

Entry: _____

Correct information: _____

Page: _____

Entry: _____

Correct information: _____

If you would like to receive periodic updates of this guide, please complete the following information.

Name: _____

Agency Affiliation (if appropriate): _____

Title (if appropriate): _____

Address: _____

City/State/Zip: _____

Telephone: _____

TTY: _____

Email: _____

I am a: Parent of a child with a disability Individual with a disability
(Check all Disability-related service provider Teacher/educator
that apply) Other (describe) _____

Contact Family Voices with your feedback by returning this form to:

Family Voices at the Rhode Island Parent Information Network
175 Main Street
Pawtucket, RI 02860
Fax: 401-727-4040
Email: familyvoices@ripin.org

Notes

Notes



175 Main Street Pawtucket, RI 02860
401-727-4144 or 800-464-3399 (RI only)
www.ripin.org or info@ripin.org

Glossary

Health Care Definitions

ACUTE CARE: Medical services provided after an accident or for a disease, usually for a short time period.

AMBULATORY CARE: Medical care provided on an outpatient (non-hospital) basis.

ANESTHETIST: Specialist in reducing pain during surgery. This is done by giving the patient anesthesia (a powerful painkiller).

ASSISTIVE TECHNOLOGY DEVICE: Any item, piece of equipment, or product system that is used to increase, maintain, or improve the daily living of a child with a disability.

AUDIOLOGIST: A hearing specialist who can diagnosis and help a person with a hearing impairment that cannot be improved by medication or surgical therapy.

CARDIOLOGIST: Specialist of the heart and blood vessels.

CARE COORDINATION: The process of having all care needs coordinated by one person.

CASE MANAGEMENT PROGRAM: A program now offered by many insurance companies, particularly for individuals who require high-cost care or have a chronic condition. Under the program, a case manager is assigned to manage a person's health needs. Contact your health insurance plan to find out if you are eligible and how it works.

CHILD WITH A DISABILITY: A child with mental retardation, hearing loss (including deafness), speech or language impairments, loss of eyesight (including blindness), serious emotional disturbance, physical impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities that need special health care or education.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS: Children who have, or are at increased risk of chronic physical, developmental, behavioral, or emotional conditions. Children with special health care needs receive more health care and services than other children.

CHRONIC CARE: Continuous care required over a period of time for people who have long-term disabilities or health problems.

CLINICIAN: All types of medical professionals who care for patients, including doctors or physicians, nurses, physician's assistants, therapists, etc.

COLLABORATIVE CARE: Working with your child's doctor to make treatment choices that are best for your child.

CONTINUITY OF CARE: When the care of a patient is continuous (without interruption) from the onset of illness until its completion. Multiple forms of care, such as health care and social services, may be provided to the patient.

CRITICAL CARE: Management of all aspects of a critically ill patient, who is usually in the Intensive Care Unit.

DERMATOLOGIST: Specialist of the skin and skin disorders.

DURABLE MEDICAL EQUIPMENT: Necessary medical equipment that is not disposable; for example, leg braces, wheelchairs, walkers, ventilators, hearing aids, commodes, etc.

EARLY INTERVENTION: A program that serves children younger than three years old with developmental delays and their families. The program provides evaluation of your child's development; in-home support; links to the community; and services to help your child.

EARLY PERIODIC SCREENING DIAGNOSIS AND TREATMENT: A program that requires that Medicaid eligible children be screened for medical, dental, vision, mental health, and developmental problems. If any problems are identified, the child is eligible to receive certain necessary treatments regardless of whether those treatments are part of your state's Medicaid plan.

EMERGENCY CARE: Immediate care that is necessary when a child has a condition, illness, or injury that is life-threatening or that would significantly harm his or her health.

ENDOCRINOLOGIST: Specialist of the organs that produce hormones, such as ovaries and testes.

ENT (EAR, NOSE, AND THROAT): A specialist who provides medical and surgical treatment of the head and neck, including the ears, nose, and throat.

FAMILY-CENTERED CARE: Health care that is based on the concerns, priorities and resources of the family. Communication between parents and medical providers is encouraged.

GASTROENTEROLOGIST: Specialist of the stomach, intestines, and related organs.

GENERIC MEDICINES: Medications that do not have a brand name, but contain the same ingredients as brand name medications. Usually, generic medicines are less expensive.

GENETICIST: Specialist of how traits of parents (including certain diseases) are given to their children.

HEMATOLOGIST: Specialist of the blood.

HOME AND COMMUNITY BASED SERVICES WAIVERS AND MEDICAID PLAN

AMENDMENTS: This program allows some children with special needs whose parents are over income limits for Medicaid to qualify for Medicaid benefits.

HOSPICE SERVICES: Care for people with terminal illnesses and their families.

INDIVIDUALS WITH DISABILITIES

EDUCATION ACT: A federal law that guarantees all children with disabilities access to free and appropriate public education.

INPATIENT CARE: When a patient is admitted into a hospital and receives care within the hospital. A patient can also receive "outpatient" care in a hospital's emergency room or ambulatory care center.

INTERNIST: Specialist of diseases of organs in the chest, abdomen, or head.

MATERNAL AND CHILD HEALTH BLOCK

GRANT: A federal grant for providing care and services to children and mothers. A certain amount of these funds must be used for children with special health care needs.

MEDICAID: Funded jointly by state and federal monies, this public program provides health care benefits for those who meet certain income requirements. In some cases, income may be waived. When Medicaid is paying for services, the providers must be approved Medicaid providers.

NEONATOLOGIST: Specialist of the care and treatment of newborn infants.

NEPHROLOGIST: Specialist of the diagnosis and treatment of kidney disorders.

NEUROLOGIST: Specialist of the nervous system. The nervous system includes the brain and spinal cord.

NEUROSURGERY: Surgery of the brain and spinal cord.

OBSTETRICIAN: Specialist of pregnancy, labor, and the period right after childbirth.

OCCUPATIONAL THERAPY: Therapy that aims to increase independence or prevent further disability through work and play activities.

ONCOLOGIST: Specialist of the diagnosis and treatment of tumors and cancer.

OPHTHALMOLOGIST: Specialist of the eyes.

OPTOMETRIST: Specialist that diagnoses vision problems and writes prescriptions for corrective lenses to preserve or improve eyesight.

ORTHOPEDIC SURGEON: Specialist of surgical prevention and correction of deformities of muscles and bones.

ORTHOTIC DEVICE: Braces that support weak

or injured joints and muscles.

PALLIATIVE CARE: Care that improves the quality of life of patients facing life-threatening illness and their families. Palliative care focuses on the prevention and relief of pain by means of early identification, assessment, and treatment. It also focuses on prevention and relief of pain and other physical, psychosocial, and spiritual problems.

PEDIATRICIAN: Specialist of the development and care of children and treatment of childhood diseases.

PHYSICAL THERAPIST: A specialist who uses exercise, temperature, electricity, ultrasound, and massage to improve physical function of a patient and prevent disability.

PLASTIC SURGERY: Reconstruction, correction, or improvement in the shape and appearance of body structures by surgery.

PREVENTIVE CARE: Medical services that try to reduce the chances of illness, injury or other conditions before they actually occur. This contrasts with acute care, which is given after the condition has occurred.

PRIMARY CARE: Routine medical care that is usually provided in a doctor's office or clinic.

PRIMARY CARE PHYSICIAN: Physicians who are pediatricians, family physicians, internists, or general practitioners.

PROSTHETIC: An artificial limb.

PROVIDER: A hospital, skilled nursing facility, outpatient surgical facility, physician, practitioner or other individual or organization that is licensed to provide medical services, therapy, or treatment.

PSYCHIATRIST: Specialist in the diagnosis, treatment, and prevention of mental disorders.

A psychiatrist may prescribe medication.

PSYCHOLOGIST: Specialist dealing with normal and abnormal mental processes and their effects upon behavior.

PULMONARY DISEASES: Diseases of the lungs.

RADIOLOGIST: Specialist in the diagnosis and treatment of disease through X rays.

RESPIRATORY THERAPY: Treatment to help the lungs work properly.

RHEUMATOLOGIST: Specialist in the diagnosis and treatment of swelling and pain in muscles or joints.

SECONDARY CARE: Medical care provided by medical specialists that usually requires a referral from a primary care physician.

SPECIALIST: A medical professional whose practice is limited to a particular branch of medicine, surgery, or research (examples: allergist, physical therapist, etc.).

SPEECH THERAPIST: Specialist using techniques to correct disorders of speech, language, swallowing/feeding, and voice.

SUPPLEMENTAL SECURITY INCOME: A federal program that provides cash and access to Medicaid (in most states) for children who have specific disabilities or chronic illnesses. To be eligible, parents must meet income criteria.

TERTIARY CARE: Very specialized medical care and services, usually provided in hospitals by highly trained specialists using the most advanced medical technology.

URGENT CARE: Care provided when a patient has an illness that is not life-threatening but that requires immediate attention.

UROLOGIST: Specialist of the urinary tract in both males and females, and the genital tract in males.

Helpful acronyms

for Families of Children with Special Needs

A

ADHD	Attention Deficit/Hyperactivity Disorder
ARC	Association for Retarded Citizens
ASD	Autism Spectrum Disorder
ASRI	Autism Society of Rhode Island
AT	Assistive Technology

C

CDC	Centers for Disease Control and Prevention
CEDARR	Comprehensive Evaluation, Diagnosis, Assessment, Referral and Re-evaluation
CF	Cystic Fibrosis
CHIP	Children's Health Insurance Program
CNA	Certified Nurse Assistant
COZ	Child Opportunity Zone
CP	Cerebral Palsy
CSHCN	Children with Special Health Care Needs

D

DCYF	Department of Children, Youth and Families
DDS	Disability Determination Services
DHS	Department of Human Services
DOE	Department of Education
DOH	Department of Health
DSSRI	Down Syndrome Society of Rhode Island

E

EFA	Epilepsy Foundation of America
EI	Early Intervention

F

FAS	Fetal Alcohol Syndrome
FIP	Family Independence Program
FOP	Family Outreach Program
FRC	Family Resource Counselor

I

IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
IFSP	Individualized Family Service Plan

L

LCSW	Licensed Clinical Social Worker
LEA	Local Education Agencies
LICSW	Licensed Independent Clinical Social Worker
LMHC	Licensed Mental Health Counselor

M

MCH	Maternal and Child Health
MD	Medical Doctor (also Muscular Dystrophy)
MHRH	Department of Mental Health, Retardation, and Hospitals
MS	Multiple Sclerosis

N

NICU	Neonatal Intensive Care Unit
NP	Nurse Practitioner

O

OSERS	Office of Special Education and Rehabilitation Services
OT	Occupational Therapy

P

PA	Licensed Physician Assistant
PAT	Parents As Teachers
PCP	Primary Care Provider
PDD	Pervasive Developmental Disorder
PNP	Professional Nurse Practitioner
PSN	Parent Support Network
PT	Physical Therapy (also Physical Therapist)

R

RIAD	Rhode Island Association of the Deaf
RIDE	Rhode Island Department of Education
RIHAP	Rhode Island Hearing Assessment Program
RIPIN	Rhode Island Parent Information Network
RN	Registered Nurse

S

SCHIP	State Children's Health Insurance Program
SILC	Statewide Independent Living Council
SLP	Speech and Language Pathologist
SPED	Special Education Department
SSDI	Social Security Disabilities Insurance
SSI	Supplemental Security Income

T

TBI	Traumatic Brain Injury
TBSCI	Traumatic Brain and Spinal Cord Injury Program
TCYC	Therapeutic Child and Youth Care
TTD or TTY	Teletype for the Deaf

U

UCPRI	United Cerebral Palsy of Rhode Island
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V

VIP-RI	Vulnerable Infants Programs of Rhode Island
VNA	Visiting Nurse Association
VNS	Visiting Nurse Services

W

WIC	Women, Infants and Children Supplemental Nutrition Program
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Acknowledgements

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