

Parent Resource Manual



All About _____

Your Child's Name

Medical Information and Resources

Parent Resource Manual

Medical Information and Resources

Revised 10/2013

This publication was developed in part with funding from the Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB)/Division of Services for Children with Special Health Care Needs (DSCSHN) through Grant# H84MC07942

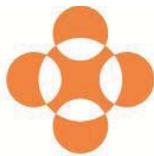
And in part with grants from Dignity Health for the Smooth Way Home Project with Feeding Matters, Southwest Human Development Easter Seals, and Raising Special Kids. For information on this NICU Parent Resource Manual, contact Raising Special Kids at 1-800-237-3007 or at info@raisingspecialkids.org

Acknowledgements

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This publication was supported by Cooperative Agreement 5U50DD000609-04 from the Centers for Disease Control and Prevention. This Cooperative Agreement is provided to the Arizona Department of Health Services, Bureau of Public Health Statistics, Project Title: AZ Population Based Birth Defects. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

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feeding matters

*Conquering pediatric feeding struggles
to nourish healthy futures*



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A Note to Parents

You are very important in your child's life! You are also an important member of your child's health care team. Think about your initial reactions when finding out your child was going to be a part of your life. You surely have hopes and dreams for your child's future. You may now have concerns for your child that you never expected. You may be feeling overwhelmed or wonder what the future holds for your family.

This notebook is designed to help you deal with the emotions of having a child with special health care needs and provide you and your family with information on how to partner with doctors and others on your health care team in order to be an effective advocate for your child. This notebook will help you plan and coordinate your child's care. It has been created by parents of children with special health care needs, as well as those who work with them.

We encourage you to find and follow your dreams, hopes, and wishes that you have for your family. There will be many opportunities for learning and growth on the road ahead. We hope this notebook will be helpful to you and your family on your journey.

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Getting Started With This Manual

- The first step in making this manual a useful tool is to organize the information you already have. Gather your child's medical records, reports and other important documents, and put them in chronological order.
- The next step is to look through this manual to determine what information about your child is important and should be included.
- Take the manual to all health care providers your child sees. This includes those your child sees regularly (primary care physician, therapies, specialists, etc.) as well as those they do not see regularly such as an emergency room or urgent care center physician. Be sure to use the manual to help you review your child's health care with any provider who is not familiar with your child.
- Track changes in your child's medicines or treatments. Make sure you share new information with your child's primary doctor, public health nurse, daycare staff, and others caring for your child.
- Ask for help. There are many people that can help you organize this manual, such as your child's primary care provider, public health nurse, case manager, other parents or other family members.
- List telephone numbers for health care providers and community organizations.
- Prepare for appointments – write down any concerns or questions you may have and bring them with you.
- Use the calendar to write down important dates and appointments.
- This manual provides a convenient and effective way for you to organize your child's medical information and makes it easier for you to find and share key information with others who are a part of your child's health care team.
- This manual is your tool; customize it to make it work for you! Not all of the pages will apply to your family situation. If a form does not concern your child, file it under the Appendix section, for future reference, if needed. You may use all or just part of the manual. You can add or remove pages according to your child's needs. Additionally, these and other forms, as well as other sources of information will be available online for your convenience to download and print as needed. For more information, visit: <http://www.raisingpecialkids.org>

Now that my baby is discharged, how do we manage at home?

Congratulations! The big day you've waited for is finally here. You are taking your baby home! Although, up until now, your baby's every breath has been monitored by trained professionals, soon all of your baby's care will be your responsibility. So, excitement is probably mixed with a lot of nervousness. Remember that it is normal to be anxious about leaving the familiarity and support of the hospital. All parents can feel that way. Be sure to ask questions and understand your instructions for at-home care, as well as for scheduled visits to the pediatrician or nurse practitioner. Being informed will help you properly chart and understand how your baby is doing. Knowing what to look for, and how to react, will allow you to have a great affect on your baby's health, growth, and development.

We are being discharged! But, now what?

Your excitement is building at the thought of bringing your baby home from the NICU. Here is a list of a few of the simple, but critical, things you should take care of as you plan for life at home with a new baby:

- Clean your house to protect your baby from dust, smoke, animal hair and germs.
- Make sure you have a car seat. Visit the American Academy of Pediatrics at www.aap.org for tips on how to choose the proper one for your newborn. Your nurse can also help you decide what kind of car seat is best for your baby and will make sure that your baby is safe in the seat before you leave the hospital.
- Have a crib, diapers, thermometer, clothing, and blankets available.
- Start using a breast pump, if planning to breast-feed, or buy several weeks' supply of formula.
- Make appointments with your baby's healthcare provider for follow-up checkups and immunizations.

Once you are prepared, you will likely have many questions about how to care for your baby at home. It is okay to ask for help or advice. Your NICU staff can be a great resource. They can help guide you through this transition. It may be scary knowing that you are now fully responsible for this tiny, new life. Focus on the following to keep your newborn healthy:

Feeding

Most premature babies are able to breast-feed or drink from a bottle before they are sent home from the hospital. It is likely that your baby will be at least as hungry as any other newborn and will need to feed eight to ten times a day. He or she will likely have six to eight wet diapers each day. Keep a chart of how much and when your baby feeds, as well as how many diapers are wet each day. This information will be helpful when you visit the doctor or nurse practitioner.

Handwashing and Care at Home

Because their immune systems are not yet fully developed, infants born early are more at risk for getting infections than older children. Understand how important it is that everything that touches your baby is clean and washed. No one should smoke in your home. All hands that touch your baby should be washed with warm water and soap. No one who is sick should visit. Try to stay at home as much as possible when you first leave the hospital with your premature baby. Except for scheduled visits to your baby's healthcare provider, try to limit trips to public places for the first several weeks.

Immunizations

Immunizations (also called vaccines or shots) are given to premature babies on the same schedule that they are given to full-term infants. Ask your baby's healthcare provider for this schedule.

When do I call the doctor?

After your baby's health was monitored 24 hours a day by trained NICU personnel, it may be a little scary for you to have to make decisions about when to contact a doctor if you believe your baby is sick. Call your baby's healthcare provider if you think something doesn't seem right to you.



Do I need special equipment?

Many infants leaving the NICU do not need special medical equipment when they leave the unit. However, some babies will be sent home with medical equipment for you to manage. If your baby is sent home with any of this equipment, make sure your NICU nurses or your baby's healthcare provider explain to you

how to properly use it. The three most common types of equipment that you might see are:

Apnea monitor—This machine is connected to your baby with soft sticky patches or with a belt around the chest. It sounds an alarm if your infant's breathing stops or if the heart is beating irregularly.

Oxygen tank—The most common reason that babies need oxygen at home is that they have lung conditions that make it hard for them to breathe on their own. Oxygen gets to your baby from the tank through soft plastic tubing that goes into your baby's nose. Remember that oxygen is extremely flammable and you must never have it in the same room where there is a burning fireplace, lit cigarettes, or sparks.

Feeding tubes and syringe—Babies, who at discharge are still unable to suck or swallow well, may still get nourishment through feeding tubes ("gavage feeding"). A flexible thin tube is inserted through the nose or mouth into the stomach. Then, you can use a syringe to deliver breast milk or formula into the tube.

Continuing medical care—When are regular doctor's visits scheduled?

Preventative medical care is very important to the growth and development of your baby. Be sure to understand that you will be making many trips to your baby's healthcare provider for immunizations and checkups. This plan to keep your baby healthy is one of the most important responsibilities you have as a parent. Ask your infant's healthcare provider for a schedule of recommended visits.

The first checkup — What happens and what information do I need to share?

The first well-baby exam usually begins with a physical exam during which a healthcare provider measures your infant's length, weight, and head circumference. He or she will mark this information on a graph to track the appropriate infant growth and development. In addition to a complete head-to-toe exam, a family

medical history will be taken, and the healthcare provider will ask questions about what the baby can do physically and how often and how much he or she is feeding. If you are unsure, nervous, or concerned about anything, this will be your chance to ask your healthcare provider about it. It is a perfect opportunity to understand what behavior and growth is considered "normal."

How do I figure out if my baby is developing normally, even though he or she was born early?

If your baby was in the NICU, you may be anxious about what proper growth and development to expect. You may even begin to compare your premature infant with full-term babies who are the same age. This can be discouraging if your baby does not seem to have mastered the same skills, or to be a size similar to full-term babies born at the same time. This is completely normal. However, take comfort in knowing that babies who are born prematurely are sometimes referred to by two different ages: "chronological" age, which is the age of the baby calculated from the baby's date of birth; and "corrected" or "adjusted" age, which is the age of the baby calculated from the baby's due date.

For information about the developmental milestones of babies who are born early, talk with your doctors and nurses, or visit the March of Dimes website at

www.marchofdimes.com/baby/growing_indepth.html.

Remember that you need to adjust your expectations of your baby's development according to his or her due date (corrected/adjusted age). Although your infant's healthcare provider will look at the changes in your baby at each well-baby visit, you will always know your baby best. Ask questions if you think your child is not progressing as you feel that he or she should.

Does my baby need special services?

As you take special care to look at your baby's development, understand that pediatricians and child development experts will evaluate a baby's skills in five developmental areas:

- Gross motor skills—how your baby moves his or her entire body
- Fine motor skills—how your baby uses his or her fingers or hands
- Language skills—how your baby verbally communicates
- Social skills—how your baby plays with toys and people
- Cognitive skills—how your baby thinks

After an evaluation, you may learn that your baby needs special professional services to deal with certain developmental delays. If these delays are spotted and treated early in life, it is more likely that a baby will overcome them or learn to deal with them effectively. Most states will allow NICU graduates to be evaluated to see if they need special supportive therapy. If your child has a delay that is eligible for supportive therapy in your state, an early intervention program will be designed and your child will get the help he or she needs.



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THE EFFECT OF A DISABILITY (*& Chronic Medical Condition*) **ON THE FAMILY**

Family members each cope with a child's disability or illness in their own way. Each member must adapt to the new situation. Relationships within the family, along with previously defined rules, values and roles must be adapted also. Such tremendous changes on everyone's part can cause much stress on the family unit, as well as on individual members.

Mothers

In the initial crisis period, mothers may react differently from fathers or significant others. Mothers may be more **emotional** and may voice concerns about their ability to cope with the additional tasks of childcare. Usually, mothers are more encouraged socially to express their feelings, and they also receive the majority of **support** offered to the family.

Because mothers are usually the **traditional caretaker** in the family, they assume most of the additional work in caring for their special child. They must learn how to make it all work together within the household routine. And, because they are doing much of the daily care, mothers may recognize and feel the **reality** of their child's disability earlier than the father.

With the responsibility for daily care often comes an additional role in the **medical world**, taking the child to clinics, school evaluations, consultations, and other services. Thus, mothers become the **primary information giver and taker** for the family.

Fathers

Fathers may respond less emotionally at first than their partners, concentrating more on **long-term concerns**, such as prognosis, social stigma, financial impact, and the child's future as an adult. It is not unusual for fathers, because of culture and family beliefs, to cope by trying to be what society expects of men, to be "strong and silent." Thus, dads are discouraged from confronting and expressing their feelings. Fathers may be expected to assume the role of the **family leader**, **"the fixer,"** and the person **in control**. These roles may be difficult to maintain, adding to the stress created by such expectations.

Fathers are traditionally the **"breadwinners"**: that is, their primary role in the family is making money to provide the family with what it needs. They may feel a tremendous responsibility for the financial burden that may accompany the disability, especially if the mother just quit her job to care for their special child. More hours working means more hours spent away from the child, less time for receiving information, and less opportunity to initiate professional and/or

supportive relationships. It is, therefore, not unusual for fathers to deny their child's disability for a longer time.

Mother-Father Relationships

The relationship between the mother and father is usually the initial bond within the family. That relationship is a **partnership**, one that sets the rules and roles for the family. Still, each parent is an individual who reacts uniquely to the crisis; and, in fact, each may define the loss differently. These individual responses or reactions can cause a crisis in itself.

When a parent utilizes his or her own coping skills in the crisis, the other parents may **misinterpret** this behavior. He or she may judge their partner's response as inappropriate within the situation, because it is different from the way they reacted. At times, mothers may label their partner's behavior as "cold," or "uncaring," when the fathers are perceived to deal with their child's situation in an "objective" manner. Fathers may judge their partners as "overly emotional," or "weak." Fathers may feel that they must take care of their partner, in spite of having unmet needs of their own. Mothers may feel the same. Each partner may be unable to see beyond his or her own needs. Each can be unaccepting of the other's way of coping. Each may become **angry** at the other for adding to the stress in an already stressful situation.

Parents may have difficulty **communicating** with each other about their child's disability. One parent may want to share feelings, but the other parent may be unable or unwilling to do so. This difference may set up a communication block and one-sided discussions. Fathers may have to rely on their partners to relay information from professionals, but the information they need may not be forthcoming. Mother may understand what they heard but be unable to explain it fully. At times, those concerns will only add to the worry or depression for their partners. Consequently, each may attempt to protect the other by avoiding such discussions.

Each parent has his or her own value system, which was handed down from their childhood family. Differences in value systems may contribute to conflicts within the relationship regarding decision-making and the outlook for their child. Thus, the parental unit may become overwhelmingly burdened and it may take much compromise to keep it intact.

The mother-father relationship can survive the many changes it must endure, but parents must work to:

- Find a way to communicate feelings and concerns in a productive manner. They may need to seek guidance in this area, especially if effective communication has not been well established in the past.

- Develop a respect for each other's coping style. This, too, may require professional guidance.

Step-Parents

When joining a new family, step-parents encounter major issues, such as attaching to the new step-child, and defining and being accepted in their role as a step-parent. Typically, it can take as long as four to seven years for a step-parent to build a strong place within his or her new family. Step-parents of a child with a disability not only have the "usual" issues of step-parents, but they also have to learn new aspects of physical care as well as deal with concerns never experienced before. They may also have to struggle to attain a role with the child, since roles have probably already been firmly defined.

Grandparents

Grandparents have an especially hard role. They, like other family members, grieve for their "dreamed of" grandchild. Grandparents often look forward to a new grandchild, envisioning themselves as a nurturer and mentor for the child; they are eager to watch them grow and develop into adulthood. Grandparents may see the child's disability or illness as an obstacle to fulfilling that dream. They may also worry about the future and the suffering their grandchild may have to endure.

They also grieve for their **own child**. It causes them much pain to see their own child's happiness shattered. They may worry that their new grandchild may become a "burden" throughout the rest of their adult child's life. They may want to protect their adult child from any additional hurt, which they soon find impossible to do. They become confused when their offers for help are not eagerly accepted. They may not understand why their child doesn't want them to "fix it." Or, they may actively deny their grandchild's disability, and be very frustrated by their own adult child's attitude regarding the child's problems.

Grandparents may find themselves experiencing situations they have never encountered before. They may be at a loss about where to seek support for their special concerns. They may also have to re-enter the caretaker role again, in order to assist their own adult child in parenting. In order for grandparents to be a valuable asset in the family, they may need to receive support for their special circumstances. They will need information to understand the disability, an avenue for expressing feelings and concerns, and encouragement that they are valued by their adult child and their grandchild.

Brothers and Sisters

The relationship between brothers and sisters is a very powerful one, providing opportunities for sharing, companionship, rivalry, loyalty, and the expression of feelings. Together, siblings often support and guide each other through

developmental tasks, teach each other social skills, and build relationships that will last a lifetime.

When brothers or sisters begin to feel the impact of their sibling's disability they will voice or demonstrate concerns and feelings that relate to their sibling status. Siblings often experience:

- **Confusion.** What is wrong? How did it happen? Although wanting to know why, children may not be able to understand the reasons, or be able to process the information shared.
- **Anger.** Why did this happen to me? Why is my new sister causing so much trouble? In addition, children often react to stress with anger.
- **Anxiety, guilt.** Did I cause it? How will it change me? They may mistakenly feel that in some way they made the problem happen.
- **Fear.** Will it get worse? Will it happen to me? Siblings may worry that the condition or disability may be contagious and will affect them also.
- **Jealousy.** Siblings may be jealous of the time their parents spend with their ill sibling, or the time parents may have to spend away from home.
- **Resentment.** They may resent the changes and sacrifices they have had to make as part of the family, as well as the time and money spent on their sibling, and not on them.
- **Embarrassment.** Especially for adolescents, the appearance of behavior of their siblings with disabilities may cause acute embarrassment.
- **Ridicule.** Siblings may have to endure ridicule from friends and peers about their "different" sibling.
- **Loneliness, depression** Siblings may feel a sense of social isolation for themselves and their family as a result of the disability.
- **Decreased self-worth.** Siblings, especially in their adolescent years, may be preoccupied about "being different" because of their siblings disability. They may be unusually worried about the future.

Certain feelings or crises can be heightened at certain ages: younger siblings who are closer in age to the child with disabilities may focus more on fear, guilt, and jealousy. School-aged siblings may experience more resentment, ridicule, embarrassment. Adolescents, many times, must deal with the ridicule of their peer group.

Regardless of age, all siblings have basic needs as part of a family with a child with special needs:

- **Need for Information.** Brothers and sisters need to understand their sibling's disability. Meeting this need may be a difficult task at times. Even though a child may be old enough to be given the information, he or she may be **too inexperienced** to understand. Explanations need to be **age-appropriate** and **ongoing**.

Many children will not ask questions. They may not know what to ask, or, they may be afraid of causing further hurt to their already suffering parents.

Adults may have to initiate information sharing, often triggered by changes in behavior, sleeping habits, or performance of the child with special needs. Along with information about the disability, siblings need to hear about the family members' feelings and concerns, and how the disability may affect each member of the family. Beginning such open and honest communication within the family may require professional guidance

- **Need for expression of feelings.** Siblings need **opportunities and permission** to express their feelings about their brother or sister. Some children do not know how to express themselves. They often learn how to act through modeling themselves after the significant others around them. When adults and other children are expressing their feelings in a productive way, siblings will be more likely to do the same.
- **Need to be their own person.** Brothers and sisters need to feel valued as both individuals and as members of the family. Siblings need to feel that they are **treated equally** by those around them, and that their personal needs will be respected.
- **Need to be involved in the decision-making of the family.** When the siblings participate in discussions about the issues that affect the whole family, they are more apt to understand and effectively cope with the decisions and their outcomes. Issues such as finances, vacations, and changes in household responsibilities are best discussed as a family.
- **Communication** is essential in all areas of brother and sister support. All family members need to share, listen, and acknowledge their crisis. Sibling support groups and other outside resources may be helpful, especially on issues relating to their peers.

Family Medical Information and Important Contacts



This section includes pages to provide your health care team with a personal profile of your child and family. These forms will help providers learn more about your child and family. Additionally, important contacts are kept in this section.



Emergency Preparedness

Children with special health care needs may have complex and unique medical histories and conditions that affect decisions about their proper treatment during an emergency. Therefore, it is critically important that emergency health providers and “first responders” (paramedics, hospital ER doctors, school nurses, etc.) can get an **up-to-date and complete record of your child’s medical issues**.

Since emergencies don’t always happen at home when a knowledgeable family member can explain a child’s health condition, the American Academy of Pediatrics and the American College of Emergency Physicians have created an “**Emergency Information Form for Children with Special Needs**”.

This 2-page **Emergency Information Form** provides important details about a child’s health, including:

- family & emergency contacts
- diagnosis/diagnoses
- doctors & specialists
- prior medical procedures
- baseline physical condition & vital signs
- current medications
- allergies
- immunizations
- recommended treatments for common health issues

Emergency Information Form for Children With Special Needs																																																																																																									
 																																																																																																									
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Specialty:		Fax:																																																																																																							
Anticipated Primary ED:		Pharmacy:																																																																																																							
Anticipated Tertiary Care Center:																																																																																																									
Diagnoses/Past Procedures/Physical Exam:																																																																																																									
1.	Baseline physical findings:																																																																																																								
2.																																																																																																									
3.	Baseline vital signs:																																																																																																								
4.																																																																																																									
Genetic:	Baseline neurological status:																																																																																																								

Get the Form:

- **Blank Form** (to print then complete by hand): <http://goo.gl/aTVusD>
- **Interactive Form** (to complete online and print): <http://www2.aap.org/advocacy/chfdataform.pdf>

Complete the Form:

Fill in as many of the answers as you can. Then, **take the Form to your child’s primary care doctor and specialists** to help you with the rest of the information. Be sure to fill in the date the form was completed (box in the upper right-hand corner) so you can check if the information is current.

Share the Form:

Make copies of the completed form and **keep a copy** in places like:

- doctors & specialists offices
- local hospital emergency room
- school or daycare
- child's backpack (and luggage when traveling)
- home on the refrigerator
- parent's workplace
- parent's wallet
- family's car
- home of emergency contact person listed on the form

Update the Form:

Review the form and make any changes every year -- or sooner, if there are any changes to your child's health condition or treatment (medications, diagnoses, surgeries, etc.).

Using the Form at School/Daycare:

Since children spend many hours away from their families, it's a good idea to have an **emergency plan** in place for school or daycare.

To develop an emergency plan for your child:

- 1) Complete the Emergency Information Form
- 2) Provide copies to your child's:
 - ✓ school nurse or designated health personnel
 - ✓ classroom teacher
 - ✓ principal
 - ✓ school bus driver
- 3) Designate an adult to be responsible for child in case of emergency (evacuation, etc.) – and, a back-up person in case that adult is unavailable.
- 4) Practice evacuation procedures (e.g. fire drill) annually with designated adults.
- 5) Update the Emergency Information Form as needed.

This school emergency plan and Emergency Information Form should be **included in your child's Individualized Education Plan (IEP) or 504 Plan.**

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Emergency Information Form for Children With Special Needs

Last name:



American Academy of Pediatrics



Date form completed	Revised	Initials
By Whom	Revised	Initials

Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:	Phone Number(s):		
Physicians:			
Primary care physician:	Emergency Phone:		
	Fax:		
Current Specialty physician: Specialty:	Emergency Phone:		
	Fax:		
Current Specialty physician: Specialty:	Emergency Phone:		
	Fax:		
Anticipated Primary ED:	Pharmacy:		
Anticipated Tertiary Care Center:			

Diagnoses/Past Procedures/Physical Exam:	
1.	Baseline physical findings:
2.	
3.	Baseline vital signs:
4.	
Synopsis:	
	Baseline neurological status:

*Consent for release of this form to health care providers

Diagnoses/Past Procedures/Physical Exam continued:

Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):
1.	
2.	
3.	
4.	Prostheses/Appliances/Advanced Technology Devices:
5.	
6.	

Management Data:

Allergies: Medications/Foods to be avoided	and why:
1.	
2.	
3.	
Procedures to be avoided	and why:
1.	
2.	
3.	

Immunizations

Dates						Dates					
DPT						Hep B					
OPV						Varicella					
MMR						TB status					
HIB						Other					

Antibiotic prophylaxis:	Indication:	Medication and dose:
-------------------------	-------------	----------------------

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations

Comments on child, family, or other specific medical issues:

Physician/Provider Signature: _____ **Print Name:** _____

Child and Family Information

Child's Name: _____ Date of Birth: _____

Family Information

Language: _____ Religion: _____

Diagnosis: _____

Blood Type: _____

Child's Legal Guardian: Mom Dad Grandparent Other _____

Guardian's Name (if other than Mom or Dad): _____

Address: _____

Home Phone: _____ Email: _____

Family Members

Mother's Name: _____

Address: _____

Email: _____

Home Phone: _____ Cell Phone: _____

Father's Name: _____

Address: _____

Email: _____

Home Phone: _____ Cell Phone: _____

Other Household Members: _____

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Child and Family Information

Other important family members and/or supportive friends: _____

What is the best way to contact them? _____

Does your child have more than one residence? Yes No

If yes, please explain: _____

Additional Parent(s)/Guardian(s)

Name: _____ Relationship to Child: _____

Address: _____

Email: _____

Home Phone: _____ Cell Phone: _____

Name: _____ Relationship to Child: _____

Address: _____

Email: _____

Home Phone: _____ Cell Phone: _____

Emergency Contact

Name: _____ Relationship: _____

Address: _____

Home Phone: _____ Cell Phone: _____

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Communication Log for Therapists / In-Home Providers

Keep track of what you have discussed with your child's various therapists and caregivers.

Date	Time in	Time Out	Person/Agency	Phone Number	Notes

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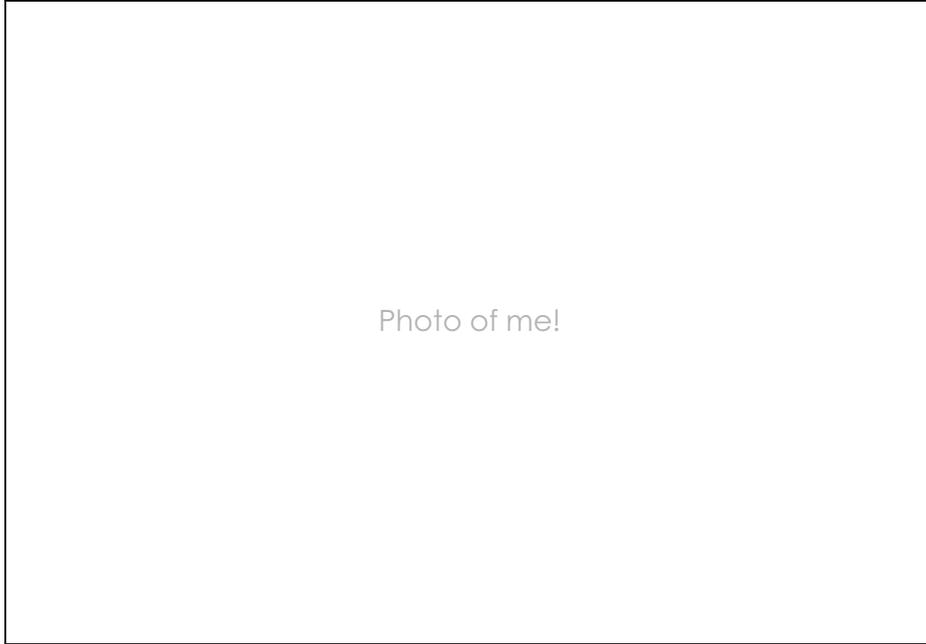
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Developmental Information



This section includes pages to allow you to record your child's developmental milestones. These forms will help providers learn more about your child's development.

Child's Page



My Name is: _____ My Nickname is: _____

My Favorites:

Toys: _____

Animals: _____

Games: _____

Songs: _____

Other: _____

My favorite foods are: _____

My least favorite foods are: _____

My friends' names are: _____

When I am happy I: _____

When I am sad I: _____

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Child's Page

When I'm not feeling good: _____

Big Accomplishments (Firsts smile, words, tooth, etc.): _____

Things I do that make my parents smile: _____

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Left Handprint

Right Handprint



Footprints

Child's Milestones

My Child	Age	Notes
Smiled		
Held Up Head		
Rolled Over		
Sat Up		
Got First Tooth		
Started Solid Food		
Crawled		
Spoke First Word		
Waved "Bye-Bye"		
Walked		
Spoke First Sentence		
Toilet Trained		
Other:		
Other:		
Other:		

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Arizona Early Intervention Program (AzEIP)

What is Early Intervention?

Early Intervention is professionals working in partnership with parents and families of children with special needs, to support their children's growth, development, and learning. Early Intervention happens in places where children and families live, learn, and play; the families' natural environments.

You know your child best.

Contact AzEIP if you have concerns about how your child:

- Plays and interacts with others
- Learns
- Communicates
- Moves
- Sees
- Hears

How do I refer my child to AzEIP?

You are now able to refer a child to AzEIP using our Online Referral:
<https://egov.azdes.gov/azeip/AzeipREF/Forms/Categories.aspx>.

If you prefer to refer your child to AzEIP by phone, or for additional information, call 602-635-9799.

Did You Know?

Raising Special Kids offers training to help parents understand the Arizona Early Intervention Program (AzEIP). This training is offered at no cost for families.

IFSP Basics

For parents of children birth to 3. Learn the basics of the process for developing an Individualized Family Service Plan.

Functional Outcomes

Helps parents identify goals for their child's IFSP (Individual Family Service Plan) or ISP (Individual Service Plan). Learn how to work with therapists and providers to support your child's developmental progress.

Call 800-237-3007 or visit: www.raisingpecialkids.org for times and locations.

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Managing Your Child's Medical Care



This section includes pages to assist you in managing your child's medical needs. It provides immediate access to information most frequently required by medical providers and others who work with your child. It is especially important that this section be kept current with up to date information.

How to Make the Most of Your Child's Health Care Visits

Questions to ask to help you choose a doctor/provider for your child:

- Do you feel comfortable with providing the additional time and care that NICU/special needs children and their parents often require?
- Is there a specific staff member I could contact for referrals?
- Is there another doctor in your office you would recommend that we visit if you are out of the office?

Preparing for your appointment:

- If you need to cancel the appointment, call your doctor/provider *at least* 24 hours in advance, if possible.
- Ask if the appointment requires a referral or other authorizations.
- Create a list of questions and/or concerns.
- Bring this binder to your appointments.
- Make sure the medication log is up to date.
- Bring a pen and extra paper so you can take detailed notes.
- Arrive at least ten minutes early.

During the appointment:

- Bring any referrals/authorizations that may be needed
- Address your questions and concerns from the list you created and any others that come up during the appointment (see below).
- Discuss any changes in your child's health since his/her last visit.
- Ask about any procedures or treatments that you are unclear about.
- Take detailed notes.

After the appointment:

- Review your notes to ensure that all of your questions/concerns have been addressed.
- If you find that you need further clarification or have more questions, contact the doctor/provider.
- If you are given a referral for another provider, schedule that appointment as soon as you get home, while it is still fresh in your mind.
- On your calendar and in your binder, fill in the date of your next appointment, or a date on which you need to schedule that appointment.

Asking Open-Ended Questions

To get the most advice and information from doctors/providers, it is important to ask questions that will generate discussion.

Examples of open-ended questions: • *What is our next step?* • *What should I look for over the next few months?* • *What concerns do you have?* • *Who do we need to see next?* • *What would you do if this was your child?*

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Doctor/Specialist Appointments

Name of Doctor:

Specialty:

Date/Time	Questions To Ask At Appointment	Notes	Referrals/Follow-Up

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Medications

Remember to include any over-the-counter medicines and supplements your child takes.

Name of Medication	Prescribing Doctor	Strength (see label)	Reason for Medication	Dosage/Frequency (amount)	Start/End Dates	Reason for Ending Medication	Out of Pocket Cost

Pharmacy

Pharmacist

Address

Phone Number

ALLERGIES: _____

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Medical Procedures

Include any procedures, surgeries, tests, lab work, etc. Provide members of your child's medical team with copies of this information.

Date of Service	Procedure	Doctor/Location	Notes/Misc

Child's Name: _____ Date of Birth: _____

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Date of Service	Procedure	Doctor/Location	Notes/Misc

Child's Name: _____

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Pharmacies that do Medication Compounding

Compounding is when a pharmacist creates one-of-a-kind medications based on the unique needs of a patient as ordered by a health care provider.

Avondale

- Walgreens 10710 W McDowell Avondale, AZ 85392 623-936-7234

Buckeye

- Walgreens 25073 W Southern Ave Buckeye, AZ 85326 623-215-1113

Casa Grande

- Walgreens 1514 E. Florence Blvd Casa Grande, AZ 85122 520-836-2787

Chandler

- Walgreens 1919 N Dobson Rd. Chandler, AZ 85224 480-899-6713
- Walgreens 3005 E Riggs Rd. Chandler AZ 85249 Ph. 480-214-1402

Coolidge

- Walgreens 1575 N Arizona Blvd. Coolidge, AZ 85128 520-723-5480

Cottonwood

- Walgreens 550 S. Main Cottonwood, AZ 86326 928-649-3850

El Mirage

- Walgreens 15385 N. Dysart Rd. El Mirage, AZ 85335 623-583-8248
- Walgreens 12244 W Cactus El Mirage, AZ 85335 623-876-1620
- Saliba's Extended Care Pharmacy 11713 W. Thunderbird Ave. El Mirage, AZ 85335 623-815-8965

Flagstaff

- Flagstaff Medical Center **77 W. Forest Ave., Ste. 104, Flagstaff 928-773-2565**
- Mortar & Pestle 2708 North Fourth Street Flagstaff, AZ 86004 928-526-2446

Gilbert

- Apothecary Shop 2450 East Guadalupe #110. Phone: 480-633-6934
- Walgreens 2450 E. Guadalupe Rd., Ste. 110 Gilbert, AZ 85234 (480) 633-6934
- Walgreens 4766 E Queen Creek Road Gilbert, AZ 85297 480-988-1908

Glendale

- Apothecary Shop 17612 North 59th Ave. 602-942-8270
- Walgreens 6006 N 67th Ave Glendale, AZ 85301 623-939-7571

Goodyear

- Walgreens - 3361 N Litchfield Rd., Goodyear AZ 85395 623-935-1314

Mesa

- Community Clinical Pharmacy – 1450 South Dobson Rd. 480-969-0600
- Rx Formulations 6047 E. University Drive Mesa, AZ 85205
- Walgreens 2737 E McKellips Rd Mesa, AZ 85213 480-835-0970
- Walgreens 1138 S. Higley Mesa, AZ 85206 480-325-3876
- Walgreens 6002 E Main St Mesa, AZ 85205 480-985-0155

Paradise Valley

- Arizona Apothecaries 10565 N. Tatum Blvd, Suite B-1 Paradise Valley, AZ 85253

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Pharmacies that do Medication Compounding

Peoria

- Potter's House Apothecary 21755 N. 77th Ave - #1200 Peoria, AZ 85382 (636) 362-9322
- Walgreens - 9050 W Union Hills Dr Peoria, AZ 85382 623-566-1986

Phoenix

- Walgreens 4315 W. McDowell Rd Phoenix, AZ 85035 602-352-0078
- Walgreens 3605 E Thomas Rd Phoenix, AZ 85018 602-275-7507
- Walgreens 2420 E Baseline Road Phoenix, AZ 85042 602-268-7232
- Walgreens 5101 W Indian School Rd Phoenix, AZ 85031 623-247-1014
- Walgreens 1620 N. 59th Ave. Phoenix, AZ 85035 623-849-2092
- Walgreens 3450 W. Dunlap Road Phoenix, AZ 85051 602-973-0971
- Apothecary Shop 5040 North 15th Avenue #102 602-277-3181
- Park Central Pharmacy 555 West Catalina 602-277-5444
- 5th Avenue Pharmacy 3411 North 5th Ave. 602-264-4697
- Genrich Pharmacy 333 East Virginia 602-257-1196
- Mixtures Pharmacy and Compounding Center 16515 South 40th Street 480-706-0620
- Advanced Health & Wellness Center 3811 E. Bell Rd, #105 Phoenix, AZ 85032 602-992-4370
- Foothills Professional Pharmacy 4545 E. Chandler Blvd Ste 100 Phoenix, AZ 85048 480-496-4444
- Mack's Pharmacy 3628 East Thomas Rd Phoenix, AZ 85018 (800) 736-0222
- Professional Pharmacy 1300 N. 12th St - Suite 300 Phoenix, AZ 85006 (602) 252-7229
- Safety Drugs, Inc. 19825 North 14th Str Phoenix, AZ 85024 (602) 482-6898
- The Compounding Center 4045 E. Bell Rd #163 Phoenix, AZ 85032 (602) 971-6950

Sedona

- Big Park Compounding Pharmacy 48 W. Cortez Dr. Sedona 86351 928-284-9593

Scottsdale

- Apothecary Shop 9777 North 91st St Scottsdale, AZ 85258 (480) 451-3771
- Civic Center Pharmacy 7331 E. Osborn Dr #208 Scottsdale, AZ 85251 (480) 945-9519
- Diamondback Drugs 2930 North Hayden Rd Scottsdale, AZ 85251 (480) 946-2223
- Scottsdale Professional Pharmacy 7350 Stetson Dr. Scottsdale, AZ 85251 (480) 946-9477
- Walgreens 6501 E. Greenway Pkwy. Scottsdale, AZ 85254 480-368-7893
- Walgreens 20631 N. Scottsdale Rd. Scottsdale, AZ 85255 480-563-2370

Sun City

- Walgreens 10707 W Peoria Ave Sun City, AZ 85351 623-974-3603
- Boswell West Pharmacy 10503 W. Thunderbird Sun City, AZ 85351 (623) 972-7868
- Walgreens 14418 W Meeker Suite 101 Sun City West, AZ 85375 623-584-8501

Surprise

- Walgreens 15490 W. Bell Rd. Surprise, AZ 85374 623-546-0032
- Walgreens 17088 W. Bell Rd Surprise, AZ 85374 623-544-0667
- Walgreens 15514 W Waddell Rd Surprise, AZ 85379 623-215-0544

Tucson

- Walgreens 6767 E. Broadway Blvd. Tucson, AZ 85710 520-290-0958
- Walgreens 3800 W Ina Road Tucson, AZ 85741 520-744-4708

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Seizure / Behavior Log

Only use this log if it applies to your child.

Date/ Time	Duration of Seizure or Behavior	Description of Seizure or Behavior <i>Include details about intensity and extremities involved</i>

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Seizure / Behavior Log

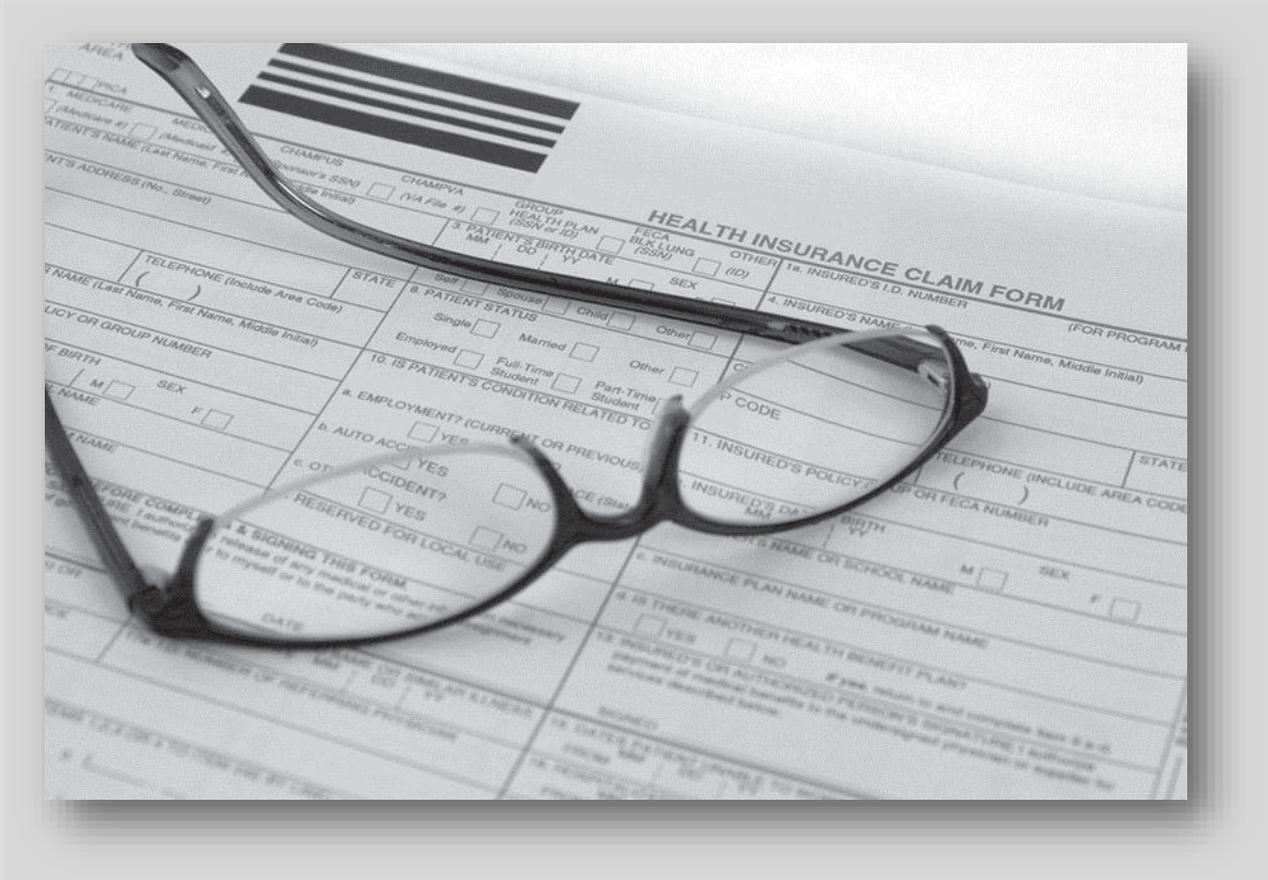
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Insurance and Finance



This section includes pages where you can record any information on health care coverage, medical bills, and out of pocket expenses.

Medical Insurance Information

Primary Insurance Company: _____

ID #: _____ Phone Number: _____

Group #: _____ Policy #: _____

Policy Holder's Name: _____

Employer's Name: _____

Employer's Address: _____

City: _____ State: _____ Zip Code: _____

Additional Insurance Company: _____

ID #: _____ Phone Number: _____

Group #: _____ Policy #: _____

Policy Holder's Name: _____

Employer's Name: _____

Employer's Address: _____

City: _____ State: _____ Zip Code: _____

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Medical Insurance Information

Additional Insurance Company: _____

ID #: _____ Phone Number: _____

Group #: _____ Policy #: _____

Policy Holder's Name: _____

Employer's Name: _____

Employer's Address: _____

City: _____ State: _____ Zip Code: _____

Other Insurance Company (*Dental, Vision, etc.*): _____

ID #: _____ Phone Number: _____

Group #: _____ Policy #: _____

Policy Holder's Name: _____

Employer's Name: _____

Employer's Address: _____

City: _____ State: _____ Zip Code: _____

A.H.C.C.C.S.

Identification Number: _____

Health Care Plan Name: _____

CRS Medical Record Number: _____

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Making the Most of Your Healthcare Dollars and/or Insurance Plan

Public Insurance:

- When you became eligible for the Arizona Health Care Cost Containment System (AHCCCS), you were enrolled in an AHCCCS or Arizona Long Term Care (ALTCS) health plan.
- Your health plan issued you a card that serves as your member identification. On the card, you will find a telephone number to reach a member services representative. For example, with Children's Rehabilitative Services (CRS), member services can:
 - answer questions about your healthcare benefits;
 - help solve a problem or concern you might have with your doctor or any part of CRS;
 - help you find a doctor, or change a doctor;
 - tell you about the doctors, their backgrounds, and the care facilities in the CRS network;
 - help you if you get a medical bill;
 - tell you about community resources available to you, and
 - help you if you speak another language, are visually impaired, need oral interpretation services, sign language services, or other accommodations.
- If you are not sure if you have ALTCS or AHCCCS; or don't know which health plan you have, you can call AHCCCS at (602) 417-4000 or 1(800) 654-8713.
- Your member handbook contains information on how and from whom to get care, what types of care are and are not covered and who to contact if you have problems. If you do not have a member handbook, request one from your health plan; or if you have access to a computer your health plan will have a member handbook on their website. There is no fee for obtaining a member handbook.
- Use your right to make a complaint or grievance. If you are dissatisfied, or have a problem with your health services, your member handbook or health plan representative can assist you in filing a complaint.

Making the Most of Your Healthcare Dollars and/or Insurance Plan

- Use your right to appeal a health plan decision such as denial or reduction of needed services. Your member handbook or health plan representative can assist you in filing an appeal.
- Request a higher level of care coordination from your health plan when you are spending additional time arranging or providing care for your child or when you have more than one health insurance plan.
- If you would like assistance working through any health care service problem, you may call or email the Office for Children with Special Health Care Needs at (602) 542-1860 or 1(800) 232-1676 or OCSHCN@azdhs.gov.
- If at any time a service that your AHCCCS doctor requests is denied, be sure the denial is in writing. You will need that document if you decide to appeal the decision. If you decide to appeal, make sure you do so within the deadline.

Private Insurance:

- Read your insurance policy; get to know it very well; carry the pages that summarize your coverage with you to medical appointments so you can refer to them if necessary.
- Call your insurance company regarding anything about your plan you do not understand.
- Before seeing a provider, call them and ask about charges, including probable procedures or laboratory tests your child routinely requires.
- Before seeing a provider, call your insurance company to determine what percentage or amount you will pay for an office visit, and what deductibles or co-pays apply.
- Tell your provider about your coverage; explain that anything not covered will be an out-of-pocket expense.
- Work out a payment plan with your provider in advance of receiving services, rather than after the fact. Many providers will want to provide the service your child needs and will work with you. If yours won't, shop for a provider who will.

Making the Most of Your Healthcare Dollars and/or Insurance Plan

- When discussing costs for a procedure or surgery, ask your provider who else will be involved and who you should be talking to regarding expected costs, for example hospital, anesthesiologist, specialists, laboratory, imaging or pharmacy.
- Negotiate with your provider. Ask them to accept the amount paid by your insurance company as full payment.
 - If your child requires a brand name medication for which there is no generic or the generic cannot be taken for medical reasons, ask your provider to write a letter of medical necessity. Submit the letter to your insurance company with a request that the medication your child requires be provided at a lower rate than other brand name prescriptions. You may find a sample letter of medical necessity at the link below or by calling Office for Children with Special Health Care Needs at (602) 542-1860 or 1(800) 232-1676:
<http://www.acdl.com/pdfs/How%20to%20Write%20Effecitve%20Ltr%20of%20Medical%20Necessity.pdf>
- If your employer has a pre-tax medical savings account option, use it. Talk to your human resources person about this and other similar plans that can save money on health care expenses.
- Read the "Explanation of Benefits" (also known as EOB) summaries you receive from your insurance company. These list the name of the provider you went to for healthcare services, how much they charged, how much the insurance company paid and how much you are responsible to pay. If something is denied, or paid at a lower rate than you expected, call your insurance company and find out why. You may be able to clarify a problem or your provider may need to submit more information.
- If you do not understand the "Explanation of Benefits" summary call your insurance company and ask for clarification. The first few times you read these they can be confusing.
- Keep all your health care papers together in a file drawer or binder, (i.e.: insurance coverage summary, handbook, EOB's, bills for services, and records of your payments.) Keep all the information about each service together.

Making the Most of Your Healthcare Dollars and/or Insurance Plan

- Keep a record of all telephone calls you have with your insurance company or provider regarding a service, claim, denial, or bill. Record the name of the person you talked with, their direct telephone number and title, the date and time you called and a summary of the discussion and outcomes.
- Any important requests you make of your insurance company should be done in writing. Keep a copy of everything you send. Have proof of when and how you sent it. A receipt for certified mail or a fax receipt can provide that record.
- A common reason that payment for a service is denied is because the insurance company did not have complete information about you and the service you need. Ask your doctor to write a letter of medical necessity. In addition to your diagnosis and a description of the service, the letter should include how long you will have this condition, what health problems will occur if you don't get the service in question and what else you did to address the problem.

No Public or Private Insurance:

If you have been denied Arizona Health Care Cost Containment System (AHCCCS), and health care costs are consuming more of your income and resources, you may become eligible for AHCCCS; therefore, keep applying.

You can apply online at

<http://www.azahcccs.gov/applicants/application/AcuteCare.aspx> for AHCCCS Health Insurance and KidsCare using Health-e-Arizona. To request an application for AHCCCS Health Insurance, KidsCare, and AHCCCS Freedom to Work, call (602) 417-7000. To request an application for Food Stamps, Cash Assistance, and AHCCCS Health Insurance, call (602) 542-9935 or 1(800) 352-8401.

- Based on your family budget, determine how much you can afford to spend on healthcare each month - be realistic.
- Before seeing a provider, inform them that you are personally paying for services; ask that they discount your bill to the lowest costs negotiated with insurance plans.
- Make sure that your provider, not just the front office or billing staff, knows that you are paying privately.

Office for Children with Special Health Care Needs/Arizona Department of Health Services
Bureau of Women's and Children's Health

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602-542-1860

Making the Most of Your Healthcare Dollars and/or Insurance Plan

- Ask the provider if the procedure, test, etc. is really necessary.
- Ask to set up a payment plan with your provider. Stay within your budget and make it clear to your provider that you are on a healthcare budget.
- Discuss costs, insurance plan discounts and payment plans with everyone who will be sending you a bill. For example a surgery will include bills from hospital, surgeons, anesthesiologists, specialists, hospitalists, pharmacies, laboratories, imaging and others. Ask your primary care provider for a list of who will be involved and who will be sending you a bill.
- Go the extra mile with the hospital, appearing in person if necessary, make sure you are getting the lowest discounted insurance rates; if the billing office can't help you go to the administration.
- Not-for-profit hospitals must provide some services, without cost, to members of their community in need. Ask whether your hospital is a for-profit or not-for-profit hospital. If it is not-for-profit, ask to speak to the person who arranges charitable care. Keep asking until you have found someone who can work with you.
- Inquire at your pharmacy about prescription discount programs. You may search, by medication name, for available patient assistance programs at http://www.pparx.org/en/prescription_assistance_programs/list_of_participating_programs.
- Call the company that manufactures your child's medication; ask them about patient assistance programs. Your pharmacist may be able to provide you with the manufacturer's contact information. If they offer no assistance programs, describe your situation and ask for the name of someone who can assist you. Keep asking, be pleasant but assertive, and describe the consequences of your child being without the medication. Ask to speak to a supervisor, ask for the person who handles the company's charitable giving, ask to speak to the CEO (you won't get them right away, but you may get someone higher up who can make decisions). Not every drug manufacturer will be able to help, but yours might.

Making the Most of Your Healthcare Dollars and/or Insurance Plan

- Use your resources. Contact disorder related support groups, both local and national; they may be able to provide information or additional resources. Browse the Arizona Department of Education, Exceptional Student Services, Parent Information Network website at <http://www.ade.state.az.us/ess/das/pinspals>.
- Locate a Community Health Center in your area at <http://www.aachc.org/>. Inquire about the availability of primary care services and discuss fees before you need to see a doctor.
- Contact your school-aged child's nurse, regarding the AFCCA Foundation for Children. The AFCCA Foundation can assist you in meeting a specific medical need such as glasses, hearing aids, medication, special equipment, course of treatment, etc. When no other resource is available, school nurses are able to apply directly to AFCCA Foundation for Children for a grant to meet the child's need. At <http://www.azfda.org> more information is available for families and school nurses.
- Contact a local community service club, and provide specific information regarding your child's need of a surgery, regular check-ups, medication, etc. Ask the club if you can present your case at a meeting and request their support of your child. If several children, with the same disorder, use one provider; a club may be interested in supporting a specific service all the children need. (For example: nutritionist services for children with Phenylketonuria (PKU).
- Contact the Social Security Administration at <http://www.ssa.gov> or 1 (800) 772-1213 and ask about the Supplemental Security Income (SSI) that pays benefits to disabled adults and children who have limited income and resources. SSI not only offers financial support but also qualifies the SSI recipient for health care coverage.
- Individuals of any age who have been without health insurance for at least 6 months and have a pre-existing condition, may qualify for the Pre-Existing Condition Insurance Plan. As part of the Affordable Care Act, this plan offers a comprehensive health plan with reasonable monthly premiums. Learn more about the plan and how to enroll at www.pciplan.com.
- Browse through the OCSHCN website or contact us at:

Office for Children with Special Health Care Needs/Arizona Department of Health Services
Bureau of Women's and Children's Health

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Making the Most of Your Healthcare Dollars and/or Insurance Plan

Arizona Department of Health Services
Bureau of Women's and Children's Health
Office for Children with Special Health Care Needs
150 North 18th Avenue, Suite 320
Phoenix, Arizona 85007-3243
(602) 542-1860 / 1 (800) 232-1676
FAX (602) 542-2589
Website: www.azdhs.gov/phs/ocshcn
E-mail: OCSHCN@azdhs.gov

The ABCs of Health Insurance: A Glossary

Affiliation Period: The time period some health plans require that you wait for your health coverage to begin after you enroll in the plan.

Appeal: Another review of a denied claim by the insurance company that gives you the opportunity to provide additional supporting information and “make your case” for approval and payment.

Benefits: The specific services covered (paid) by a health insurance plan.

Benefit Exclusion: Conditions or services NOT covered by your health policy.

Benefit Limitation: The plan will pay for the service -- but limit the coverage (e.g. it will pay only for a certain number of therapy visits annually).

Capitated Rate: A set, prepaid amount that a health plan pays a doctor or other health care provider for all services provided to a plan member.

Certificate of Creditable Coverage: If you switch health plans, your former health plan should send you this document. KEEP IT! It shows your new plan how long you had health coverage with the old plan. If your new plan has a **Pre-Existing Condition Exclusionary Period** (meaning they won't pay any related claims for a certain time period), you will be given “credit” for time you were covered under the old plan, and your waiting time will be reduced.

Certificate of Insurance: THE detailed description of the **Benefits, Limitations** and **Exclusions** for your health plan. Generally, your insurance company will provide this information to the purchaser of the plan -- your employer, not you. BE SURE TO GET A COPY FROM YOUR EMPLOYER AND READ IT CAREFULLY!

Claim: Your request to the insurance company for payment for health care services that you received.

COBRA: A federal law that lets you continue to purchase health insurance for up to 18 months if you lose your job or your coverage is otherwise terminated. The cost of this continued coverage is paid by the employee or dependent that elects it – and, is usually rather expensive. Employers with less than 20 employees generally are not subject to COBRA, so they do not have to offer you the option of continuing your health insurance after you leave your job.

Co-insurance: The amount that you pay after you pay the amount of your **Deductible** – usually, a percentage of the charges. For example if you have a \$500 deductible and you have an “80/20” plan, you pay the first \$500 of medical expenses submitted to your health insurance. After the \$500, your insurance will pay 80% of the charges, and you pay 20%.

Co-pay: The amount you pay for a particular service under your particular insurance plan. For example, you pay \$25 co-pay for an office visit, then the health insurance will pay some or all of the rest of the doctor's charges (depending on whether you have a **Deductible** or **Co-insurance**).

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The ABCs of Health Insurance: A Glossary

Deductible: The amount of your health care costs you have to pay before your health insurance even begins to pay.

Denial: The refusal by your health plan to pay for medical services you received or requested.

Durable Medical Equipment: Medical equipment that you need to treat your condition that is not disposable (e.g., wheelchairs, walkers, ventilators, etc.).

Enrollment Period: The time period during which employees and their dependents can sign up for coverage under an employer group health plan.

Exclusion: A medical or health care service that is NOT paid for by your health plan. A list of exclusions can be found in your **Certificate of Insurance**.

Explanation of Benefits (EOB): The insurance company's written explanation to a claim, showing how much of a charge they paid and how much you must pay.

Fee-for-Service Plan: Health care coverage allows you to visit the provider of your choice, with your insurance company paying a set percentage of the amount billed for each service performed. You pay the remainder. Fee-for-Service is also called "Indemnity" or "Traditional Plan".

Flexible Spending Account: A benefit that may be offered by your employer in which you select a certain amount of your salary deducted – BEFORE BEING TAXED – from your paycheck and put into a separate account for medical expenses. As you pay for things not covered by your health plan (like co-pays, glasses, dental work, hearing aid batteries, and other expenses excluded from your health plan), you can essentially "reimburse" yourself for these expenses. If you have a lot of "out-of-pocket" medical expenses, this is something to consider. One drawback – you can't get reimbursed for your monthly health insurance premiums. Also, if you don't use it annually, you can lose it. Also called "Medical Reimbursement Account."

Formulary: The list of prescription drugs (by specific name) that your insurance will pay for – and, the accepted dosages, forms and conditions for each drug.

Fully Insured Group Plan: A type of employee health plan in which the insurance company (not the employer) is financially responsible for all claims. These plans are regulated by the state of Arizona's Department of Insurance, not the U.S. Department of Labor (see **Self-Insured Group Plan**).

Guaranteed Issue: A HIPAA requirement that a health plan must enroll you regardless of your health status, age, disability, claims history or any other factor that might predict your use of health services.

Guaranteed Renewability: A HIPAA requirement that a health plan cannot cancel you just because you get sick.

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The ABCs of Health Insurance: A Glossary

Health Savings Account (HSA): An HSA allows you to set aside money tax-free to pay for current and future health expenses. You own and control the money in your HSA – you decide how much to deposit, where to invest it, and how to spend it. HSA contributions are tax deductible and earn interest tax free, and there's no income limit for an HSA owner. Also, HSA funds accumulate from year to year – you don't "use it or lose it" like in a Flexible Spending Account. *HOWEVER, you must be covered by a **High Deductible Health Plan** to set up an HSA.* And, you can't be covered by any other health insurance, enrolled in Medicare, or claimed as a dependent on someone else's tax return.

High Deductible Health Plan: Also called "catastrophic health insurance". A health plan that won't begin to pay your medical expenses until you have paid a minimum of \$1,050 per individual or \$2,100 per family. Your monthly premium may be lower and you can participate in a **Health Savings Account** if you opt for a High Deductible plan, so if you are generally healthy and have low medical expenses, you may save money with this type of health coverage.

HIPAA: A federal law enacted in 1996 that protects security and privacy of your health information, and adds protections for people in group health plans.

HMO: Health Maintenance Organization. A type of managed care health plan in which you pay the same monthly premium for services from a network of doctors, hospitals, labs, specialists and other health care providers.

Letter of Medical Necessity: A letter written by your doctor or other health care provider to the insurance company that explains the medical need for the health care service they prescribed. This letter is helpful to include when filing an appeal.

Lifetime Maximum Benefit: The maximum dollar amount that your health plan will pay for all covered expenses during your lifetime. There may be a limit per individual or family, per specific illness or diagnosis (e.g. cancer, AIDS), per type of expense (e.g. hospitalization). Be sure to check your plan's **Certificate of Insurance** for details.

Managed Care Plan: A general term for the type of insurance plan that attempts to manage the costs and quality of health care services by limiting your access to a **Network** of doctors and specialists. **HMOs** and **PPOs** are example of managed care plans.

Medical Deduction: Medical and dental costs (e.g. co-pays, prescriptions, mileage to doctor's appointments and IEP meetings, eyeglasses) are deductible on your federal income tax return if they add up to more than 7.5% of your family's adjusted gross income. Check with an accountant or IRS Publication 502 for more info.

Network: The specific group of doctors, specialists, hospitals, therapists, pharmacies, and other health care providers who contracts with your **Managed Care Plan** to provide you health care services.

Out-of-Pocket Costs: The money you have to pay toward your health care costs – including **Deductibles** and **Co-pays**. If your plan has high out-of-pocket costs, you might want to consider a **Flexible Spending Account** to save some money.

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The ABCs of Health Insurance: A Glossary

Pre-Admission Review or Certification: Your health plan may require that you get prior approval from an insurance company representative (usually a nurse) before you are admitted to a hospital or in-patient facility. Sometimes your doctor will contact the insurance company, but you are ultimately responsible to get the authorization if you want your claim to be paid. If it's an emergency situation and you cannot call, a family member needs to call your health plan soon after you have been admitted to get approval. The purpose of the pre-admission review is to make sure that you are not getting medical services that are not necessary.

Pre-existing Condition: A health problem you have that was diagnosed or treated sometime during the six months before your new health insurance coverage starts.

Pre-existing Condition Exclusionary Period: The time period that your insurance company can limit or not pay at all for services you receive for a **Pre-Existing Condition**. The exclusion period must begin on your enrollment date. It can generally last no longer than 12 months (unless you enroll late, then it can last 18 months.).

Before a pre-existing condition exclusion can be applied to your coverage, the plan's consumer materials **must tell you** if the plan imposes pre-existing condition exclusions. And, your group health plan **must** send you a written notice that an exclusion will be imposed on you. The notice should describe the length of the exclusion period because you do not have enough creditable coverage. The notice also should describe how you can demonstrate how much **Creditable Coverage** you have.

The exclusion period must be shortened by one day for each day of creditable coverage that you have. If the amount of creditable coverage you have is equal to or longer than the exclusion period,

No exclusion period can be imposed on you. After the exclusion period is over, you should receive coverage for treatment of your pre-existing condition.

Point of Service (POS) Health Plan: A type of **Managed Care Plan** that combines the features of an **HMO** and a **Fee-for-Service Plan**. When you obtain medical services from within the **Network**, you pay a **Co-pay** of the cost (typically \$5 to \$15), like in an HMO. However, unlike an HMO, you may go out of network for health care -- however, it costs more (typically, you pay a **Deductible** and a percentage of the cost -- often 40% to 50%).

Preferred Provider Organization (PPO): A **Managed Care Plan** that is a cross between an **HMO** and a **Fee-For-Service Plan** (similar to a **POS**). Like an HMO, a PPO may still require you to select a **Primary Care Physician** from within the **Network**, and pay a **Co-pay** for your office visits. However, like a fee-for-service plan, you can see a specialist outside your network without a **Referral**, and your PPO plan will pay a percentage of the cost. This greater freedom does have a price: generally, with a PPO plan, you pay an annual **Deductible** and a higher **Premium** than an HMO.

Premium: The amount of money that you and/or your employer pay to buy health insurance. Premiums may be paid monthly, quarterly, or yearly.

Primary Care Physician (PCP): The doctor within a **Managed Care Plan's Network** that you choose to provide you with basic health care and **Referrals** to specialists.

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The ABCs of Health Insurance: A Glossary

Referral: The authorization from your **PCP** (doctor) to seek treatment from a specialist. Generally, if you want your health plan to pay for specialist services, you need a referral from your PCP before you receive medical care. See your **Summary of Benefits** or **Certificate of Insurance** for your plan's specific details.

Self-Insured Group Plan: A health plan in which your employer decides to act as its own insurance company and assume the financial risk of paying providers. The employer sets aside funds to pay for employees' health claims directly to providers. However, an employer may hire an insurance company to administer the self-insured plan, so it may look like a fully insured plan. Your employer must disclose in your benefits information if your plan is self-funded. Important note: self-insured plans are regulated by the federal Department of Labor – not the **Arizona Department of Insurance**.

Summary Plan Description: This document outlines your insurance plan's **Benefits** -- information about the coverage of **Dependents**, what services will require a **Co-pay**, and the circumstances under which your employer can change or terminate a health benefits plan. This summary is fine – but, once again – GET AND READ THE **CERTIFICATE OF INSURANCE** for the REAL details about your plan (like **Benefit Limitations** and **Exclusions**). And, don't forget to save the summary, the certificate of insurance – and, any other health plan info from the insurance company or your employer.

Waiting Period: The time period you may have to wait to be eligible for health benefits from your employer. Not all employers require waiting periods, but if yours does, your **Pre-Existing Condition Exclusionary Period** begins on the first day of the waiting period -- not the later date that you enroll in a health plan.

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Health Insurance Resources

Agencies & Organizations:

Arizona Association of Community Health Centers (AACHC)

700 East Jefferson Street Suite 100
Phoenix, Arizona 85034
602.253.0090
info@aachc.org
<http://www.aachc.org>

ADHS Office for Children with Special Health Care Needs

150 N. 18th Ave. #320
Phoenix, AZ 85007
602-542-1860
<http://www.azdhs.gov/phs/ocshcn/>

Arizona Center for Disability Law

5025 E. Washington St., #202
Phoenix, AZ 85034
602-274-6287
800-927-2260 (Toll Free Voice/TTY)
877-327-7754 (Toll Free TTY)
center@acdl.com
<http://www.acdl.com>

Arizona Department of Insurance

2910 N. 44th St., #210
Phoenix, AZ 85018-7269
602-364-2499
800-325-2548 (Toll Free)
consumers@id.state.az.us
<http://www.id.state.az.us>

Kids Health Link

800-235-9678
www.kidshealthlink.org

Raising Special Kids

5025 E. Washington St., #204
Phoenix, AZ 85034
602-242-4366
800-237-3007 (Toll Free)
info@raisingspecialkids.org
www.raisingspecialkids.org

Links & Publications:

- **Health Insurance Marketplace**
www.healthcare.gov
- **Find Local Help Applying for Health Insurance**
<https://localhelp.healthcare.gov/>
- **A Consumer Guide to Health Care Appeals**
<http://goo.gl/SDy8B> (source: AZ Dept of Insurance)
- **How to Get the Services You Need When Your Private Health Plan Tells You “No”**
<http://goo.gl/3NA3C> (source: AZ Center for Disability Law)
- **Health Care Appeal Request Form** (use to file with your insurance company)
<http://goo.gl/CsL1F> (source: AZ Dept of Insurance)
- **Plain Language Thesaurus For Health Communications**
<http://goo.gl/s7a4w> (source: National Center for Health Marketing)

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Providers and State Agencies



This section includes pages that provide you with information about providers and state agencies that offer programs your child may be eligible for.

This section is also where you could include copies of your child's Individualized Family Service Plan (IFSP). If you have not received copies, be sure to request them from your Service/Support Coordinator.

State Agencies and Providers

ABDMP – Arizona Birth Defect Monitoring Program

The Arizona Birth Defect Monitoring Program (ABDMP), within the Arizona Department of Health Services, conducts surveillance of specific birth defects across Arizona. ABDMP publishes this data and provides valuable information about birth defects and their trends in our state. ABDMP also works in the areas of prevention and referral to services for families and children affected by birth defects.

The goals of ABDMP include the following:

- To collect complete and accurate information about children born in Arizona with reportable birth defects
- To share birth defect data with health professionals, researchers, and the public, so we may better understand birth defect trends and outcomes; and identify potential areas for prevention education.
- To effectively promote known birth defect prevention strategies
- To ensure that the families and children affected by birth defects have appropriate care and support services

For more information about ABDMP, contact us at 602-364-1302 or ABDMP@azdhs.gov, or visit <http://azdhs.gov/phs/phstats/bdr/index.htm>

AHCCCS – Arizona Health Care Cost Containment System

AHCCCS is Arizona's Medicaid agency that offers health care programs to serve Arizona residents. Individuals must meet certain income and other requirements to obtain services.

To apply for AHCCCS call: **602-417-4000** or **800-654-8713** or visit:

<http://www.azahcccs.gov/applicants/application/AcuteCare.aspx?ID=acute>
<http://healthearizona.org>

ALTCS – Arizona Long Term Care System

ALTCS is the State of Arizona's Medicaid program that provides long term care services, at little or no cost, to financially and medically eligible Arizona residents who are aged, blind, disabled, or have a developmental disability. The Arizona Health Care Cost Containment System (AHCCCS) determines ALTCS financial & medical eligibility.

To apply for ALTCS call: **602-417-6600** or visit:

<http://www.azahcccs.gov/applicants/application/ALTCS.aspx>

AzEIP - Arizona Early Intervention Program

The Arizona Early Intervention Program (AzEIP) provides services for families of children, **birth to three**, who have a developmental delay or disability.

AzEIP's mission is to build upon and provide supports and resources to assist family members and caregivers to enhance children's learning and development through everyday learning opportunities, such as feeding, bath time, sleeping, and playtime.

If you have concerns about your child's development you can call AzEIP directly at 602-532-9960 or 888-439-5609 (toll free) or visit: www.azdes.gov/azeip.

This publication was developed in part with funding from the Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB)/Division of Services for Children with Special Health Care Needs (DSCSHN) through Grant# H84MC07942

And in part with grants from Dignity Health for the Smooth Way Home Project with Feeding Matters, Southwest Human Development Easter Seals, and Raising Special Kids. For information on this NICU Parent Resource Manual, contact Raising Special Kids at 1-800-237-3007 or at info@raisingspecialkids.org

State Agencies and Providers

CRS - United Healthcare Arizona Physicians IPA - Children's Rehabilitative Services

CRS provides family-centered medical treatment, rehabilitation, and related support services for children under age 21 with qualifying chronic and disabling conditions, that are enrolled in the Arizona Health Care Cost Containment System (AHCCCS).

For more information about CRS, visit: <http://azahcccs.gov/Commercial/CRS.aspx>

CRS Enrollment Unit: 602-417-4545 or 1-855-333-7828

DDD - Division of Developmental Disabilities

The AZ Department of Economic Security's Division of Developmental Disabilities (DDD) provides supports and services to eligible people with autism, cerebral palsy, epilepsy, or cognitive disability. For people who qualify for AZ Long Term Care System (ALTCs), DDD coordinates & contracts with providers for acute & long-term care services. For people with a qualifying diagnosis but don't meet ALTCs functional levels, DDD coordinates community resources — but doesn't provide services.

Phone: 602-542-0419 or 866-229-5553

You can apply for DDD services online at the following web address:

https://ddd.azdes.gov/ddd/EligibilityReferral/frm_EligibilityRequirements.aspx

Magellan of Arizona

Magellan of Arizona is the state-contracted Regional Behavioral Health Authority (RBHA). Magellan provides services to Medicaid, non-Medicaid eligible residents in central Arizona. Magellan serves recipients as well as their family members through a wide range of services from crisis assistance to housing programs to children's services and substance abuse treatment.

800-564-5465 (Toll Free)

800-424-9831 (TTY)

Crisis Line

800-631-1314 (Toll Free)

800-327-9254 (TTY)

Español

800-564-5465 (Líneas gratuitas)

800-424-9831 (TTY)

Línea de Crisis

800-631-1314 (Líneas gratuitas)

800-327-9254 (TTY)

<http://www.magellanofaz.com>

Raising Special Kids is Arizona's Family to Family Health Information Center. If you have any questions about how to navigate the systems and services available in Arizona, please contact us at: 602-242-4366

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Things You May Need for a Financial Eligibility Interview

When applying for public program services and/or benefits you may be requested to provide the following things for an interview to determine eligibility. Be sure to ask for a list of any information that is needed to complete your eligibility interview if you are not provided with one.

- Proof of Income (last 30 days pay stubs, tax return, letter from your employer)
- Proof of Residency (Mortgage payment stub, signed rental contract/agreement, utility bill)
- Proof of Citizenship or legal residency (birth certificate, visas, immigration documentation)
- Proof of Identity (driver's license, state issued identification)
- Social Security Numbers (for parents and child/children)
- Proof of Age (birth certificate, school records)
- Guardianship Papers (copies of signed court documents)
- Unearned Income and Child Support (check stubs, court orders, award letters from Social Security Administration, etc.)
- Child Care (bills and paid receipts)

Medical Expenses (paid and unpaid medical bills, drugstore prescription receipts, hospital bills, insurance premium notices, receipts for medical equipment paid for out of pocket)

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Community Resources and Family Support



This section includes pages where you can find information, contact numbers, and web links to agencies that provide community assistance.



Raising Special Kids

Families Helping Families



Raising Special Kids began in 1979 as a grassroots effort of families, professionals, and community leaders to provide support and information for parents of children, from birth to age 26, with the full range of disabilities and special health care needs. Today, Raising Special Kids is a 501(c)(3) nonprofit organization that supports thousands of Arizona families each year with disability-related resources, information, training, and support. Programs are offered at no cost to families, and are available in English and Spanish.

Raising Special Kids Helps Families

Our Family Support Team contacts newly referred families within 48 hours of receiving the referral. Families have an opportunity to share their concerns, ask questions, and receive assistance from an experienced support team. Services we provide include:

Parent Support

Families are connected with veteran “mentor” parents who have walked a similar path, and who understand the challenges of raising a child with a disability or special health care need.

Health Care Information

Raising Special Kids provides families with information about public programs and health care systems, community resources, early intervention, and working with professionals. Families receive information to help them make informed decisions regarding their children’s care.

Special Education Information

Raising Special Kids provides training and consultation in special education to families, schools, teachers, and other professionals.

Transition to Adulthood

To make a successful transition to adult life, young adults with disabilities and their families benefit from information and support to make effective decisions about graduation, housing, transportation, work, college, selecting a doctor, and coordinating medical insurance and other services. Raising Special Kids provides resources and guidance to assist families in helping youth on the journey to adulthood, including information on guardianship and other options.

Training & Workshops

Workshops are available for families to gain knowledge and information beneficial to parenting children with disabilities or special healthcare needs. A complete listing may be found at www.raisingpecialkids.org.

5025 E. Washington Street, Suite 204 Phoenix, AZ 85034
602-242-4366 • Flagstaff 928-444-8802 • Tucson 520-441-4007 • Yuma 928-444-8803 • 800-237-3007
Fax 602-242-4306 • Tucson 520-441-8981 • Flagstaff/Yuma 928-239-9838
info@raisingpecialkids.org • www.raisingpecialkids.org

Why Professionals Refer Parents to Raising Special Kids

Parent to Parent Support is an evidence-based practice to assist families by matching them with other families who have children with similar needs, concerns, and challenges.

Any parent or caregiver of a child with a disability may be referred, and confidentiality is always protected. Our referral form can be downloaded from www.raisingpecialkids.org.

Services are provided at no cost to families and are available in Spanish and English.

To create better outcomes for families through collaboration between parents and professionals.

Why Professionals Partner with Raising Special Kids

A Physician Residency Training program which includes a visit to the home of a child with a disability through our trained Volunteer Family Faculty network.

Programs designed for pre-service teachers in regular and special education related to special education services, Individual Education Plans (IEP's) and Section 504's.

In Service Training for professionals in education, healthcare, or social services on working more effectively with families on issues relating to disabilities and special health conditions.

Families Helping Families

Data from 2012

Families Assisted

7656

Parent-to-Parent Matches

333

Professionals Trained

2205

Community Partners

190

Affiliations & Certifications

Parent Training and Information Center

Raising Special Kids is Arizona's Parent Training and Information Center (PTI), one of over 100 centers authorized under the Individuals with Disabilities Education Act (IDEA) to provide assistance in special education to families and schools.

Family-to-Family Health Information Center

Raising Special Kids serves as a Family-to-Family Health Information Center funded by the U.S. Department of Health & Human Services, Maternal and Child Health Bureau. Family-to-family centers employ parents of children with special health care needs who have experience navigating complex health care and social service systems to help other parents facing similar circumstances.

Family Voices

Raising Special Kids is the Arizona chapter of Family Voices, a national network which advocates for health care services and provides information for families with children and youth with special health care needs.

P2P USA

Raising Special Kids is the Arizona chapter and a Founding Member of P2P USA, a national nonprofit committed to promoting evidence-based practices in access, quality and leadership in parent to parent support.

WHY FEEDING MATTERS

Feeding struggles affect up to **45%** of typically developing children and up to **80%** of developmentally disabled children.

Feeding is complex. A single swallow requires the use of **26 muscles** and **6 cranial nerves**.

Eating is a **vital function for survival** and development. When children are unable to eat they **cannot thrive** cognitively, physically, or emotionally. **Early intervention is critical.**

Feeding struggles are often **underlying symptoms** for over **204 diagnoses** such as autism, cystic fibrosis, cerebral palsy, and congenital heart defects.

Over a million infants and children nationwide are identified with severe feeding struggles. **Thousands more go undiagnosed.**

PARENTS. We, the founding mothers who struggled to feed our own children, hear you—and your voice matters. Our dedication is driven by the necessity to minimize the challenge for families with feeding struggles. Between our personal experience with the problem and our partnership with the medical community, our hub of resources provides the support, expertise, and hope that families need.

MEDICAL COMMUNITY. Our thought leaders have created tools and resources to help establish best practices that foster collaborative approaches to care. With an increased understanding of the complexities of pediatric feeding struggles and the promotion of coordinated care, our medical community has the power to positively impact every child's well-being and future. Take your place at the table to transform the landscape of pediatric feeding struggles.

SUPPORTERS. Join the Feeding Matters® team on our mission to transform the landscape of feeding struggles to positively impact the lives of infants and children. Your role is crucial in continuing our efforts to bring a previously shadowed issue to the forefront. Your generosity matters; there's not a better time than now to take your place at the table.



feeding matters

8711 E. PINNACLE PEAK RD. #333 • SCOTTSDALE, AZ 85255
P 602.222.6222 TF 800.233.4658 F 602.222.6225

feedingmatters.org • support@feedingmatters.org



feeding matters



Conquering pediatric feeding struggles
to nourish healthy futures



YOUR STORY MATTERS.

“When your child doesn’t enjoy eating for medical, physical, or psychological reasons, a parent can feel frustrated, confused, and worst of all, alone. Many people don’t understand

that eating isn’t as simple as placing a plate of food in front of a hungry child and expecting them to eat. Our son Jack suffers from Eosinophilic Esophagitis Disorder, which made eating solid food an unpleasant experience. By the age of 12 months, we realized he wasn’t just a “picky” eater, but that eating was painful.

Upon our first experience with Feeding Matters®, we finally found what we were looking for.

This is a group of parents, medical professionals and advisors who know exactly how we feel. They are there to guide and empathize with us. They are knowledgeable regarding feeding therapists in our area, intensive feeding programs out of state, and they put us in contact with other parents whose children were in similar situations to ours. They gave us the educational tools to help make the right decisions regarding our child.

As our son continues to make significant improvements with regards to his feeding struggles, we are very thankful to Feeding Matters®. Their support and knowledge assisted our family at a very difficult time. We attribute much of our success to their guidance.”

Children with feeding struggles **matter**. Take your place at the table by supporting the cause. Visit feedingmatters.org.

Our mission is to bring pediatric feeding struggles to the forefront so infants and children are identified early, families’ voices are heard, and medical professionals are equipped to deliver collaborative care.

We overcome the complex issues of pediatric feeding struggles through our five mission pillars:

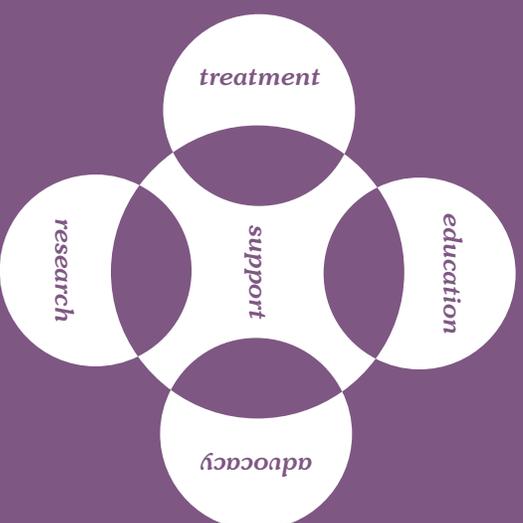
EDUCATION. Develop informative tools to educate families, medical professionals, and the community.

ADVOCACY. Propagate the awareness of feeding struggles to expand advocacy efforts and reform.

RESEARCH. Ignite and facilitate research to identify best practices.

TREATMENT. Foster collaborative approaches to care.

SUPPORT. Provide interactive and virtual resources to support families and medical professionals.



PARENTS

We, the founding mothers, who struggled to feed our own children, hear you—and your voice matters.



RESPECT. Every family is heard, valued, and supported.

TRUST. Every family deserves mealtimes that reinforce positive parent-child relationships.

CONFIDENCE. Every family is equipped with the knowledge to articulate their child’s specific needs.

INTEGRITY. Every family has access to critical information in order to make the best choices.

DIGNITY. Every family has individual capabilities and values that are accepted and honored.

*Conquering pediatric feeding struggles
to nourish healthy futures*



Birth to Five Helpline and Fussy Baby Program 1-877-705-KIDS (5437)

The Birth to Five Helpline is Arizona's only toll-free helpline for parents, families and caregivers of children ages birth to five who have questions about early childhood development. The Birth to Five Helpline serves all socioeconomic groups and can be particularly helpful for families at risk for abuse and/or neglect.

Unlike many helplines, the Birth to Five Helpline is answered by early childhood specialists, not volunteers. In addition, callers are able to access support from Southwest Human Development's wide range of early childhood staff, including psychologists, counselors, registered nurses, disabilities specialists, early literacy specialists and occupational, physical and speech-language therapists.

Topics addressed include:

- Sleeping Problems
- Behavior Problems
- Health and Nutrition
- Safety
- Potty Training
- Feeding/Eating Problems
- Fussiness/Colic
- General Child Development

The Birth to Five Helpline is available Monday through Friday from 8 a.m. to 8 p.m.

The Fussy Baby Program, an extension of the Birth to Five Helpline and part of the Erickson Institute in Chicago, provides telephone support and home visitation in Maricopa County for parents with babies who cry excessively during their first months of life. Excessive crying is enormously stressful for parents and may set up a cycle of infant-parent distress leading to negative consequences in future years. In some cases, inconsolable crying triggers child abuse including Shaken Baby Syndrome.

Fussy Baby Program results show decreases in maternal depression and parenting stress, and increases in maternal self-efficacy, all of which have a critical impact on the baby and his or her ability to grow and thrive.



Funding provided by



First Things First (FTF), approved by Arizona voters, works to ensure that our youngest children have access to quality early childhood experiences so they will start school healthy and ready to succeed. Across the state, FTF regional partnership councils – in collaboration with local leaders – identify the education and health needs of children from birth through age five in their communities and fund strategies to address those needs.

**Southwest Human Development is the Easter Seals affiliate for central and northern Arizona
2850 N. 24th Street • Phoenix, Arizona 85008 • p (602) 266-5976 • f (602) 274-8952 • www.swhd.org**



**southwest
human
development**

Parent Coaching and Support Services

Assisting families to help their children reach their fullest potential

The Parent Coaching and Support Services program provides assistance to families raising children ages birth to five who may be concerned about their child's development or may have questions about parenting their child.

Services include:

- **Home Visits:** Individual visits in the family's home or other preferred location to offer guidance on enhancing their child's development and ongoing developmental screenings
- **Parent-Child Play Groups:** Parent-child socializations in a play setting with brief presentations on topics of interest
- **Training:** Workshops for parents that focus on common parental concerns and topics of interest to them. Examples include: "Making mealtimes enjoyable," "Help your child understand and use language to communicate" and "Learning to play-playing to learn."

How does the Program Work?

Our parent coaches all have experience and expertise in working with families whose young children have delays or disabilities. They can help parents learn about child development, including what to expect and when to be concerned. The parent coaches are knowledgeable about community resources and can help program families access them.

Who Is Eligible?

Families with children ages birth to five who have concerns about their child's development, but are not eligible for state-funded special needs services. Families must reside within specific zip codes. Please contact us for more information about areas served through this program.

**For more information about Parent Coaching and Support Services,
please call (602) 468-3401 or email pcss@swhd.org**

Funding provided by



First Things First (FTF), approved by Arizona voters, works to ensure that our youngest children have access to quality early childhood experiences so they will start school healthy and ready to succeed. Across the state, FTF regional partnership councils – in collaboration with local leaders – identify the education and health needs of children from birth through age five in their communities and fund strategies to address those needs.

**Southwest Human Development • Easter Seals Southwest Human Development
2850 N. 24th Street • Phoenix, AZ 85008 • p (602) 266-5976 • f (602) 274-8952 • www.swhd.org**

THE EMILY CENTER



AT PHOENIX CHILDREN'S HOSPITAL
CHILDREN'S HEALTH INFORMATION FOR ARIZONA'S FAMILIES.

Because
Information
Offers
Hope



Free
Information
About Child
Health And
Illness

We are open to the public

- Look through our **library** of thousands of books, videos, CDs, and articles
- **Registered nurses** help you find answers to your questions
- We have books and videos about child health **for children, too**
- Use our **computers** to search the Internet and health databases
- Find our **books & videos** on Phoenix Public Library's website: www.phxlib.org
- Information can be **mailed** to you

Our Staff is here to help you and your family

Founded in 1990, the Center is named after Emily Anderson. Emily fought a rare form of leukemia for four years before losing her battle a few days before her seventh birthday.

Frustrated by the lack of easy to understand information about Emily's illness, her parents founded The Emily Center so that families of sick children would always have access to pediatric health information that is accurate, easy to understand, and free of charge.

We are open:

Monday - Friday
9:00am-7:00pm

Saturday - Sunday
10:00am-4:00pm

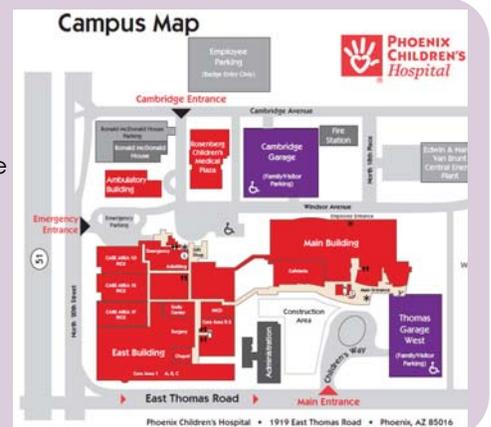
The Emily Center at
Phoenix Children's Hospital
1919 E. Thomas Road
Phoenix, AZ 85016-7710
Phone: (602) 933-1400

Outside Metro Phoenix:
(866) 93EMILY • (866) 933-6459

Email: emilyc@phoenixchildrens.com
www.theemilycenter.org

Se ofrece información en español

The Emily Center is located in the East Building on the main campus of Phoenix Children's Hospital, located on the corner of 20th Street and Thomas Rd, just off SR 51 (Piestewa Peak Parkway). Turn South on 20th Street. Turn right on Cambridge. Parking is free in the Cambridge garage.



Make A Donation

The Emily Center at Phoenix Children's Hospital is completely funded by the proceeds from special events and donations from individuals, foundations, and corporations. Please mail your tax-deductible donation to:

The Emily Center at Phoenix Children's Hospital
1919 E. Thomas Road, Phoenix, AZ 85016



The Most Comprehensive Pediatric Health Library in the Southwest.

Get Dental Care for Your Baby

- Check your baby's gums and teeth once a month. Look for white spots. If you see white spots, take your baby to a dentist right away.
- Take your baby to the dentist by the time she is 1 year old to have her teeth and gums checked.

Keep Your Own Mouth Healthy

- Brush your teeth with a soft toothbrush and toothpaste with fluoride, twice a day, after breakfast and before bed.
- Floss once a day before bedtime.
- Eat healthy foods, like whole-grain products, dairy products, fruits, vegetables, meat, fish, chicken, eggs, beans, and nuts.
- Eat fewer sweets like candy, cookies, or cake. Drink fewer sugary drinks like fruit-flavored drinks or pop (soda). Eat sweets or drink sugary drinks at mealtimes only.
- Get dental care.



Resources

Finding a Dentist

- <http://www.aapd.org/finddentist>
- <http://www.ada.org/ada/finddentist/advancedsearch.aspx>
- <http://www.knowyourteeth.com/finddentist>

Finding Low-Cost Dental Care

- <http://www.nidcr.nih.gov/FindingDentalCare/ReducedCost/FLCDC.htm>

Finding Health Insurance Coverage

- <http://www.coverageforall.org>

Cite as: Holt K, Barzel R. 2009. *A Healthy Smile for Your Baby: Tips to Keep Your Baby Healthy*. Washington, DC: National Maternal and Child Oral Health Resource Center.

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This publication was made possible by grant number H47MC00048 from the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services (DHHS). Permission is given to photocopy this publication or to forward it, in its entirety, to others. Requests for permission to use all or part of the information contained in this publication in other ways should be sent to the address below.

National Maternal and Child Oral Health Resource Center
Georgetown University
Phone: (202) 784-9771

E-mail: OHRCinfo@georgetown.edu
Website: <http://www.mchoralhealth.org>



A Healthy Smile for Your Baby

Tips to Keep Your Baby Healthy



Taking care of your baby's gums and teeth is important. Clean your baby's gums or brush your baby's teeth, give your baby healthy foods, and take your baby to the dentist by the time he is 1 year old. If you take care of your teeth, it will help your baby's teeth stay healthy, too.

Children need healthy teeth. Healthy teeth help them to chew and to speak clearly. Baby teeth also make space for adult teeth. Babies need to have their teeth brushed. Before they have teeth, you should clean their gums.

Give your baby a healthy start! Here are tips to keep your baby's gums and teeth healthy.



Take Care of Your Baby's Mouth

- Clean your baby's gums after every feeding even before her first teeth come in. Use a clean, damp washcloth or a toothbrush with soft bristles and a small head made for babies.
- When your baby gets her first tooth (usually around 6 to 10 months), begin brushing her teeth with toothpaste with fluoride (fluoride) twice a day. Use a small smear of toothpaste.



- Brush the front and back of your baby's teeth. Lift her lips to brush at the gum line of her front teeth.
- If your baby has sore gums from a tooth coming in, give her a cold teething ring, cool spoon, or cold wet washcloth. Or you can rub your baby's gums with a clean finger.
- Germs can pass from your mouth to your baby's mouth. Do not test a bottle with your mouth to see if it is too hot. Use a different spoon to taste your baby's food. If your baby's bottle nipple or pacifier falls on the floor, clean it with water.
- Do not dip pacifiers in sweet foods like sugar, honey, or syrup.

Give Your Baby Healthy Foods

- Breast milk is best! Breastfeed your baby for 6 months or longer if you can. If you feed your baby formula, use formula with iron. Wait until your baby is 1 year old before feeding him cow's milk.
- Hold your baby while feeding him breast milk or formula in a bottle.
- Do not put your baby to sleep with a bottle filled with breast milk, formula, juice, or sugary drinks like fruit-flavored drinks or pop (soda).
- Wait until your baby is 6 months old before giving him juice. Serve juice in a cup. Do not give your baby more than 4 to 6 ounces of juice each day. Give your baby 100-percent fruit juice only.
- When your baby is around 4 to 6 months old, start giving him solid foods. Do not give your baby solid foods before he is ready. One way to tell if your baby is ready is if he can sit by himself without holding on to anything.
- As your baby begins to eat more solid foods and drink from a cup, you can wean him from the bottle. Begin to wean your baby from the bottle slowly, at about age 9 to 10 months. By age 12 to 14 months, most babies can drink from a cup.
- Do not give your baby sweets, like candy, cookies, or cake, or sugary drinks.



Community Resources

24-HOUR HOTLINES

Community Information and Referral

2-1-1 within Arizona

877-211-8661 (toll free)

www.cir.org

Birth to Five Helpline

Southwest Human Development

1-877-705-KIDS

<http://www.swhd.org/get-help/birth-to-five-helpline>

ALCOHOL AND MENTAL HEALTH CRISIS COUNSELING

EMPACT-Suicide Prevention Center - 24-Hour Crisis Hotlines

800-656-HOPE -- RAINN Sexual Assault Hotline (National)

800-SUICIDE -- HopeLine Suicide Hotline (National)

480-784-1500 -- Suicide/Crisis Hotline (Maricopa County)

866-205-5229 -- Toll-Free Sexual Assault Hotline (Arizona)

480-736-4949 -- Sexual Assault Hotline (Maricopa County)

800-796-6762 or 520-622-6000--Community-wide Crisis Line (Pima County, for individuals experiencing a behavioral health crisis. Clinicians are available 24 hours a day, 7 days a week.)

www.empact-spc.com

Alcoholics Anonymous

1320 E. Broadway Rd. Suite 105 Mesa, Arizona 85204

(480) 834-9033 -- 24 hour AA Hotline

(480) 827-1905 office

info@aamesaaz.org

National Council on Alcoholism and Drug Dependence (NCADD)

4201 North 16th Street, Suite 140, Phoenix, AZ 85016

602-264-6214

800-NCA-CALL (Hope Line)

phoenix.az@ncadd.org

<http://www.ncadd-phx.org>

Centro de Amistad

2923 North 33rd Avenue Phoenix, AZ 85017-5201

602-393-3840

This publication was developed in part with funding from the Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB)/Division of Services for Children with Special Health Care Needs (DSCSHN) through Grant# H84MC07942

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Community Resources

CHILD ABUSE/NEGLECT REPORTING

Child Protective Services

Office Location: 3221 N. 16th Street #400, Phoenix, AZ 85016

1-800-SOS-CHILD

www.azdes.gov/dcyf/cps/

CRISIS HOTLINES

Childhelp Child Abuse Hotline

2346 N. Central Ave., Phoenix, Arizona 85004-1329

602-271-4500

1-800-422-4453

www.childhelp.org

Crisis Nursery

2334 East Polk Street, Phoenix, Arizona 85006

602-273-7363

<http://www.crisisnurseryphx.org>

Child Crisis Center East Valley

604 W. 9th Street, Mesa, Arizona

480-969-2308

<http://childcrisis.org/>

Parent Assistance Hotline (PAH)

Information for parents or guardians on the process of the removal of a child from their home.

602-452-3580

800-732-8193 (toll free)

<http://www.azcourts.gov/improve/ParentAssistanceHotline.aspx>

Poison Control (Banner)

800-222-1222

DOMESTIC VIOLENCE/SEXUAL ABUSE

CASA - Center for Prevention of Abuse & Violence

77 E. Thomas Road, Suite #112 Phoenix, AZ 85012

602-254-6400

www.casacares.org

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Community Resources

National Domestic Violence Hotline

800-799-7233

<http://www.thehotline.org/>

Phoenix Family Advocacy Center

602-534-2120

<http://www.acfan.net>

Rape, Abuse, Incest National Network (RAINN)

800-656-4673

www.rainn.org

PREGNANCY AND BREASTFEEDING

Crisis Pregnancy Center (Hope Center)

224 S. Kendrick St., Flagstaff, AZ 86001

928-774-8302

877-205-2178 (toll free)

<http://www.hopecpc.org>

Teen Outreach Pregnancy Services

480-668-8800 (East Valley Office)

623-334-1501 (West Valley Office)

www.teenoutreachaz.org

ADHS Pregnancy/Breast Feeding Hotline

800-833-4642 (toll free)

http://www.azdhs.gov/phs/owch/hot_line.htm

La Leche League

602-234-1956

<http://www.llli.org>

CHILD CARE

Association for Supportive Child Care

3910 South Rural Road, Suite E, Tempe, AZ 85282

800-535-4599

www.asccaz.org

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Community Resources

Arizona DES Child Care

602-255-3729

www.azdes.gov

COUNSELING

Arizona Baptist Children's Services (ABCS)

800-678-0648

www.abcs.org

Phoenix Interfaith Counseling

Central Phoenix: 602-248-9247

Northeast Valley: 602-992-7521

West Valley: 602-943-2999

East Valley: 480-317-9868

<http://www.phx-interfaith.org>

Black Family and Child Services

1522 East Southern Ave., Phoenix, AZ 85040

602-243-1773

info@bfcsfamily.org

www.bfcsfamily.org

Catholic Charities

602-749-4405

<http://catholiccharitiesaz.org>

CASA - Center for Prevention of Abuse & Violence

2200 N. Central Ave, suite 203, Phoenix, AZ 85004

602-254-6400

www.casacares.org

Family Involvement Center

5333 N 7th St. Suite A-100 Phoenix, Arizona 85014

602-288-0155

www.familyinvolvementcenter.org

Family Service Agency

2400 N. Central Ave., Suite #400, Phoenix, AZ 85004

602-264-9891

www.fsaphoenix.org

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Community Resources

Friendly House

201 E. Durango St. Phoenix, AZ 85004

602-258-4353

<http://www.friendlyhouse.org>

Jewish Family and Children's Services

4747 N. 7th St., Phoenix, AZ 85014

602-279-7655

<http://www.jfcsaz.org>

Native American Community Health Center

4041 North Central Ave. Building C, Phoenix, AZ 85012

602-279-5262

<http://www.nativehealthphoenix.org/>

Southwest Behavioral Health

3450 N. 3rd St., Phoenix, AZ 85012

602-265-8338

info@sbhservices.org

www.sbhservices.org

Southwest Human Development - Fussy Baby Hotline

2850 North 24th St., Phoenix, AZ 85008

1-877-705-KIDS

www.swhd.org

Tempe Social Services

3500 S. Rural Rd. 2nd floor, Tempe, AZ 85282

480-350-5400

<https://www.tempe.gov/index.aspx?page=2336>

Terros, Inc.

3003 North Central Ave Ste 200, Phoenix, AZ 85012

602-685-6000 ext. 1950

www.terros.org

Touchstone Behavioral Health

6153 West Olive Ave., Suite 1 Glendale, AZ 85302-4564

623-930-8705

frank.saverino@touchstonebh.org

www.touchstonebh.org

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Community Resources

Westside Social Services

8802 N. 61st Avenue Glendale, AZ 85302

(623) 934-1991

http://www.turnanewleaf.org/outpatient_counseling

Fresh Start Women's Resource Center

1130 E. McDowell Rd., Phoenix, AZ 85006

602-252-8494

www.wehelpwomen.com

EDUCATIONAL/MEDICAL INFORMATION

Emily Center - Phoenix Children's Hospital

1919 East Thomas Rd., Phoenix, AZ 85016

(602) 933-1400

Toll-free: 866-933-6459

www.phoenixchildrens.com/emily-center

March of Dimes

3550 N. Central Avenue, Suite 610, Phoenix, AZ 85012

602-266-9933

<http://www.marchofdimes.com/arizona/>

Raising Special Kids

5025 East Washington Street, Suite 204 Phoenix, AZ 85034-2005

602-242-4366

info@raisingspecialkids.org

www.raisingspecialkids.org

EMPLOYMENT & JOB TRAINING

Arizona Call-A-Teen Youth Resources

649 N. 6th Ave., Phoenix, AZ 85003

602-252-6721

<http://www.acyraz.org/>

AZ DES Jobs Program

866-299-6757

<https://www.azdes.gov/jobs/>

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Community Resources

AZ Women's Education & Employment (AWEE)

Central Phoenix
640 North 1st Ave., Phoenix, AZ 85003
602-223-4333

North Central Phoenix
914 W. Hatcher
Phoenix, AZ 85021
602-371-1216
www.awee.org

Maricopa Skill Center

Maricopa Skill Center
1245 East Buckeye Rd., Phoenix, AZ 85034

Nothwest Campus
2931 W Bell Road
Phoenix, AZ 85034

Cutting Edge
7565 West Peoria Avenue
Peoria, AZ 85345
602-238-4300
<http://www.maricopaskillcenter.com>

Phoenix Job Corps

518 South Third St., Phoenix, AZ 85004
602-254-5921
<http://phoenix.jobcorps.gov>

St. Joseph the Worker

1125 West Jackson, Phoenix, AZ 85007
602-417-9854
info@sjwjobs.org
www.sjwjobs.org

FOOD ASSISTANCE PROGRAMS

St. Mary's Food Bank

602-242-FOOD (3663)
www.firstfoodbank.org/

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Community Resources

AZ DES Nutrition Assistance Program

602-542-9935

800-352-8401 (toll free)

www.azdes.gov/nutrition_assistance

Emergency Food Assistance Program (TEFAP)

Hunger Relief Coordinator

Linda Hamman

602-542-5071

Lhamman@azdes.gov

Salvation Army Family Services

2702 East Washington St., Phoenix, AZ 85034

602-267-4100

www.tsasw.org

WIC - Women Infants & Children Program

150 North 18th Avenue Suite #310 Phoenix, AZ 85007

602-542-1025

www.azwic.gov

GOVERNMENT SUPPORT & FINANCIAL ASSISTANCE

(See Providers and State Agencies section)

AZ DES Nutrition Assistance Program

602-542-9935

800-352-8401 (toll free)

www.azdes.gov/nutrition_assistance

AZ DES Cash Assistance Program

602-542-9935

800-352-8401 (toll free)

www.azdes.gov/cash_assistance

AZ DES Utility Assistance Program

602-542-6600

800-582-5706

<https://www.azdes.gov/main.aspx?id=3336>

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Community Resources

HOUSING

Phoenix Housing Department (Section 8)

830 E. Jefferson St., Phoenix, 85003

602-534-1974

<http://phoenix.gov/housing>

Community Housing Partnership

609 North 9th St., Phoenix, AZ 85006

602-253-6905

US Department of Housing & Urban Development (HUD)

One North Central Avenue, Suite #600 Phoenix, AZ 85004

602-379-7100

<http://goo.gl/TT4wn>

Glendale Community Housing Division

6842 N. 61st Ave., Glendale, AZ 85301 623-930-2180

<http://www.glendaleaz.com/housing/>

Housing Authority of Maricopa County

8910 N. 78th Avenue, Building D

Peoria, AZ 85345

602-744-4500

<http://www.maricopahousing.org>

Mesa Housing Authority

20 East Main Street Suite 250 Mesa, AZ 85201

480-644-3536

<http://www.mesaaz.gov/housing/>

Scottsdale Community Assistance Office

7515 E. 1st St., Scottsdale, AZ 85251

(480) 312-7647

<http://www.scottsdaleaz.gov/assistance/housing>

Tempe Housing Services

21 East 6th St. Suite 214 Tempe, AZ 85281

480-350-8950

<http://tempe.gov/housing>

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Community Resources

LEGAL ASSISTANCE

Arizona Foundation for Legal Services & Education

4201 N. 24th St., Suite 210, Phoenix, Arizona 85016-6288

602-340-7366

<http://www.azflse.org>

Lawyer Referral Service

303 E. Palm Lane, Phoenix, AZ 85004

602-257-4434

<http://maricopalawyers.org/>

Arizona Coalition Against Domestic Violence - Legal Advocacy Hotline

2800 N. Central Ave., Suite 1570 Phoenix, AZ 85004

602-279-2900

800-782-6400 (toll free)

602-279-7270 (TTY)

acadv@acadv.org

<http://azcadv.org>

Community Legal Services

305 South 2nd Ave., Phoenix, AZ 85003

602-258-3434

800-852-9075 (toll free)

<http://www.clsaz.org>

Arizona Center for Disability Law

5025 E Washington St # 202 Phoenix, AZ 85034-7439

602-274-6287

www.acdl.com

Maricopa County Superior Court-Self Service Center

101 West Jefferson Street, 1st Floor

Phoenix, AZ 85003-2243

602-506-7353

ssc@superiorcourt.maricopa.gov

<http://www.superiorcourt.maricopa.gov/superiorcourt/self-servicecenter/>

Maricopa County Child Support Division

201 West Jefferson St., Phoenix, AZ

602- 252-4045 (Please request the Applications Department)

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Community Resources

<http://www.clerkofcourt.maricopa.gov/>

Orders of Protection (Phoenix Municipal Court)

300 West Washington St., Phoenix, AZ 85003
602-262-6151
www.phoenix.gov/COURT/oop.html

Salt River Pima Indian Community

10005 East Osborn Rd., Scottsdale, AZ 85256-4019
480-850-8000
<http://www.srpmic-nsn.gov/government/court/>

MEDICAL & DENTAL PROGRAMS/CLINICS

AZ Dept. of Health Services - Arizona Immunization Program

150 N. 18th Ave., Suite 120 Phoenix, AZ 85007
602-364-3630
<http://www.azdhs.gov/phs/immun/iapcoor1.htm>

Baby Arizona

800-833-4642
<http://www.babyarizona.gov>

Boys & Girls Clubs of Metropolitan Phoenix

2645 North 24th St., Phoenix, AZ 85008
602-954-8182
info@bgcmp.org
www.bgcmp.org

Adelante Healthcare

9520 West Palm Lane, Suite 200 Phoenix, AZ 85037
623-583-3001
<http://www.adelantehealthcare.com>

JC Lincoln Children's Dental Clinic

9201 N. Fifth St., Phoenix, AZ 85020
602-331-5792
<http://www.jcl.com/desert-mission/childrens-dental-clinic>

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Community Resources

Maricopa County Public Health Department

1645 East Roosevelt St., Phoenix, AZ 85006
602-506-6900
<http://www.maricopa.gov/publichealth>

Mountain Park Health Center

6601 W. Thomas Road, Phoenix, AZ 85033
Phone: 602-243-7277
<http://www.mphc-az.org>

Native American Community Health Center

4041 North Central Ave. Building C, Phoenix, AZ 85012
602-279-5262
<http://www.nativehealthphoenix.org/>

Phoenix Children's Hospital

1919 East Thomas Rd., Phoenix, AZ 85016
602-933-1000
<http://www.phoenixchildrens.com/>

South Central Family Health Center

33 W. Tamarisk, Phoenix, AZ 85041
602-344-6400
<http://southcentralfamilyhealthcenter.org/>

St. Vincent De Paul Medical and Dental Clinic

602-261-6868
<http://www.stvincentdepaul.net/PS-VirginiaGPiper.htm>

PARENTING/SKILLS SUPPORT

Chicanos Por La Causa, Inc.

1112 East Buckeye Rd., Phoenix, AZ 85034
602-257-0700
info@cplc.org
www.cplc.org

Child and Family Resources

2830 W. Glendale Ave.
Phoenix AZ 85051
602-234-3941

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Community Resources

cfr@cfraz.org

www.childfamilyresources.org

City of Phoenix - Family Services Center

914 W. Hatcher Rd., Phoenix, AZ 85021

602-495-5229

<http://phoenix.gov/humanservices/programs/emergency/family>

My Child's Ready

480.304.9440

mychildsready@childcrisis.org

<http://www.childcrisis.org/mychildsready/>

Parenting Arizona

6741 N. 7th St., Phoenix, AZ 85014

602-248-0428

<http://www.parentingaz.org>

Phoenix Indian Center, Inc.

4520 North Central Avenue, Suite 250 Phoenix, Arizona 85012

602.264.6768

<http://www.phxindcenter.org/>

Raising Special Kids

5025 East Washington Street, Suite 204 Phoenix, AZ 85034-2005

602-242-4366

info@raisingspecialkids.org

www.raisingspecialkids.org

Single Parents Association, Inc.

www.singleparents.org

Southwest Human Development

2850 North 24th St., Phoenix, AZ 85008

602-266-5976

www.swhd.org

Teen Outreach Pregnancy Services

480-668-8800 (East Valley Office)

623-334-1501 (West Valley Office)

www.teenoutreachaz.org

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Community Resources

SHELTERS

Central Arizona Shelter Services

230 South 12th Ave., Phoenix, AZ 85007

602.256.6945

<http://www.cassaz.org>

Crisis Nursery - Child Abuse Shelter

2334 East Polk St., Phoenix, AZ 85006-3916

602-273-7363

<http://www.crisisnurseryphx.org>

House of Refuge Sunnyslope

9835 N 7th St. Phoenix, AZ 85020

602-678-0223

info@houseofrefuge.us

<http://www.houseofrefuge.us>

UMOM New Day Centers, Inc.

3333 East Van Buren St.

Phoenix, AZ 85008

602-275-7852

umom@umom.org

<http://www.umom.org>

SPECIAL NEEDS

American Academy of Pediatrics

141 Northwest Point Boulevard

Elk Grove Village, IL 60007-1098

847-434-4000

www.aap.org

American Academy of Pediatric Dentistry

211 East Chicago Avenue, Suite 1700

Chicago, IL 60611-2637

(312) 337-2169

www.aapd.org

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Community Resources

American Partnership for Eosinophilic Disorders (APFED)

PO Box 29545
Atlanta, GA 30359
Phone: (713)493-7749
mail@apfed.org
www.apfed.org

Arizona Center for Disability Law

5025 E Washington St # 202 Phoenix, AZ 85034-7439
602-274-6287 | www.acdl.com

Arizona Consortium for Children with Chronic Illness (ACCCI)

2034 E Southern Ave. Suite G, Tempe, AZ 85282
480-557-8445
accci@qwestoffice.net
www.accci-az.org

Birth to 5 Helpline

1-877-705-KIDS

Bright Futures for Families

www.brightfuturesforfamilies.org

Childrens Choices

www.childrenschoices.org

Community Information and Referral

602-263-8856
800-352-3792 (toll free)
www.cir.org

Desert Sky Mothers of Multiples

dsmom09@gmail.com
<https://www.bigtent.com/groups/dsmom>

Down Syndrome Network

PO Box 12495
Tempe AZ 85284
480-759-9150
info@dsnetworkaz.org
<http://www.dsnetworkaz.org>

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Community Resources

Feeding Matters

8711 E Pinnacle Peak Road #333
Scottsdale, AZ 85255
(602) 222-6222
(800) 233-4658 (Toll-free)
<http://www.feedingmatters.org/>

Sharing Down Syndrome Arizona

745 N Gilbert Rd #124 PMB 273 Gilbert, AZ 85234
480-926-6500
gina@sharingds.org
www.sharingds.org

Southwest Human Development

2850 North 24th St., Phoenix, AZ 85008
602-266-5976
www.swhd.org

Foundation for Blind Children

1235 East Harmont Dr., Phoenix, AZ 85020
602-331-1470
info@seeitourway.org
www.seeitourway.org

March of Dimes

3550 N. Central Avenue, Suite 610, Phoenix, AZ 85012
602-266-9933
888-663-4673 (toll free)
AZ601@marchofdimes.com
www.marchofdimes.com/arizona/arizona.asp

National Hospice and Palliative Care Organization

www.nhpco.org

National Information Center for Children and Youth with Disabilities

1-800-695-0285
nichcy@aed.org
www.nichcy.org

Raising Special Kids

5025 East Washington Street, Suite 204 Phoenix, AZ 85034-2005

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Community Resources

602-242-4366

info@raisingspecialkids.org

www.raisingspecialkids.org

Ryan House

110 W Merrell St, 1st floor, Phoenix, AZ 85013

602-200-0767

info@ryanhouse.org

www.ryanhouse.org

Spina Bifida Association of Arizona

1001 East Fairmount Ave., Phoenix, AZ 85014

602-274-3323

office@sbaaz.org

www.sbaaz.org

United Cerebral Palsy

1802 West Parkside Ln. Phoenix, AZ 85027-1322

602-943-5472

info@acpofaz.com

www.ucpofaz.org

Zero to Three

www.zerotothree.org

SUPPORT GROUPS

Alanon / Alateen

602-249-1257

1-888-425-2666 (toll free)

www.al-anon.org

Alcoholics Anonymous - Hotline

602-264-1341

Desert Sky Mothers of Multiples

dsmom09@gmail.com

<https://www.bigtent.com/groups/dsmom>

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Community Resources

Down Syndrome Network

PO Box 12495
Tempe AZ 85284
480-759-9150
info@dsnetworkaz.org
<http://www.dsnetworkaz.org>

Feeding Matters

8711 E Pinnacle Peak Road #333
Scottsdale, AZ 85255
602-222-6222
800-233-4658 (Toll-free)
<http://www.feedingmatters.org/>

MISS Foundation

77 E. Thomas Road, Suite 112
Phoenix, Arizona 85012
602-279-6477
888-455-6477 (Toll-free)
info@missfoundation.org
www.misschildren.org

Mothers of Supertwins

(631) 859-1110
www.mostonline.org

Multiple Joys

abcmom@cox.net - Kathleen Anderson
<http://multiplejoys.com>

Narcotics Anonymous

480-897-4636

Parenting Arizona

6741 N. 7th St., Phoenix, AZ 85014
602-248-0428
<http://www.parentingaz.org>

Postpartum Depression

1-888-434-MOMS (Warmline)
<http://azpostpartum.org/>

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Community Resources

PreemieCare

(631) 859-1110

www.preemiecare.org

Raising Special Kids

5025 East Washington Street, Suite 204 Phoenix, AZ 85034-2005

602-242-4366

info@raisingspecialkids.org

www.raisingspecialkids.org

Sharing Down Syndrome Arizona

745 N Gilbert Rd #124 PMB 273 Gilbert, AZ 85234

480-926-6500

gina@sharingds.org

www.sharingds.org

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A Family Guidebook



Supporting Development of Newborns and Infants



This guidebook and others are available at www.eicolorado.org



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Director, Center for Family and Infant Interaction
JFK Partners Department of Pediatrics and Psychiatry,
University of Colorado Denver

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Introduction

This guidebook is provided to you by Early Intervention Colorado, a program for infants and toddlers birth through two years of age who have special developmental needs. If you or someone who cares about your child has concerns about his or her development, Early Intervention Colorado is here to help. You can request a free evaluation at any time to answer questions about your child's development and determine whether your child may benefit from early intervention supports and services. To get connected to your local early intervention program, call 1-888-777-4041 or visit www.eicolorado.org.

If you are already connected to Early Intervention Colorado, the information in this guidebook may be particularly helpful as your family works to develop your child's Individualized Family Service Plan (IFSP). To learn more about the IFSP development process as well as to obtain additional information about the early intervention system in Colorado, there are multiple family guidebooks available. You can download these guidebooks at the Early Intervention Colorado website (www.eicolorado.org) or you can request pre-printed copies of the guidebooks by contacting the Early Intervention Colorado program in your community (1-888-777-4041).

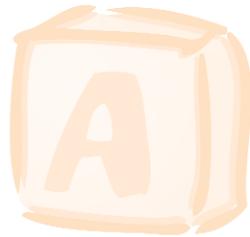
The purpose of this guidebook is to help you understand how babies grow and how important you are in helping your baby's development. The information in this guidebook can be used for all babies, including those who are in a neonatal intensive care unit (NICU).

The Building Blocks of Infant Development

In the months following the birth of your baby, you will see amazing changes happen right before your eyes. You will see more skills develop during the first three years than at any other time in your baby's life. Even if your baby was born early or with medical concerns, you will see how much he wants to learn about the world when he looks at, listens to, and touches you and things around him. He will also begin to tell you what he needs through his activity, will show delight getting to know you, and will begin to get around on his own.

Many of these skills will develop over the first year, when babies are working hard at laying the important building blocks for later development. Building blocks for newborns and young BABIES include becoming steady and organized in their:

- **B**ody function organization
- **A**wake and sleep times
- **B**ody movement
- **I**nteractions with people
- **E**ating
- **S**elf soothing



You play the most important role in helping your baby to have a solid and secure start. Your baby will tell you both what is easy and what is hard for him as he tries to handle each developmental building block. You can help him become steady in his growth by understanding how he communicates with you and then providing what he needs.

Body Function Organization

A young baby works on keeping his breathing, skin color, and temperature steady when he is touched and held. Even when sound, light, or activity levels around him change, he is able to keep his body steady. Other signs of organization are:

- Having regular breathing and a regular heart rate

- Digesting food
- Urinating and defecating

During pregnancy the mother's body controls all of her baby's body functions. After the baby is born, those functions need time to adjust and become steady. If your baby started out in a hospital NICU (a special nursery for infants born early or who need extra medical care), medicine and machines may have kept these body functions regular. It takes weeks and sometimes months for babies to keep those body functions steady, especially when they are born early or have medical complications.

Many babies are sensitive to loud sounds, bright lights, being handled, or activity around them. You may see these babies react by a change in their breathing or skin color. Gagging, hiccoughing, or bowel movement straining might also show that babies are sensitive to what happens around them.

Here are some examples of how you might expect a typical infant to show body function organization:

- Keeps a stable pink skin color except when crying
- Breathes evenly, regularly, and without too much effort (about 40–60 times a minute)
- Does not have long pauses (more than 10–15 seconds) between breaths
- Has several wet diapers every day
- Has a dirty diaper at least once a day
- Recovers quickly after getting the hiccoughs

When babies have steady body functions, it provides solid building blocks for:

- Adjusting to new experiences
- Being with sisters and brothers
- Living in a house with a busy family
- Being touched, moved, and handled
- Adjusting to change
- Listening, looking, and following



Awake and Sleep Times

Being awake to look at parents' faces, listen to voices, and take in the world are parts of baby activity that help build the foundation for later learning. Throughout the first year, a baby's sleeping and waking times are still developing, and she may not have predictable times, or cycles, when she is awake and asleep. Sleeping for longer times and sleeping through the night also take time to mature and may take a few weeks to many months to become regular.

Medical complications in the newborn period and early birth can further disrupt the development of regular sleep cycles. Babies may not sleep through the night until they are well into their first year, and when they do sleep it may be for only short periods of time. For these babies, it can be hard work to wake up and look at people's faces and listen to their voices, especially when there is a lot going on around them. Babies might be overwhelmed with too much to look at and listen to and may instead close their eyes and stay asleep, turn away, or become fussy.

Here are some examples of how you might expect a typical baby to manage sleeping and awakening:

- Has times when you can count on her being awake and times when she will sleep
- Sleeps 3–4 hours at a time, especially at night
- Wakes up gradually, not by crying suddenly

- When she cries, can be helped to wake up with some support like talking to her or picking her up
- Goes to sleep on her own when she is sleepy and can be put into her bed and stay asleep
- Wakes up when it is time to eat
- Wakes up to sudden noises but is able to “tune out” or ignore other sounds that happen over and over

When babies have steady waking and sleeping patterns, it provides solid building blocks for:

- Sleeping through the night
- Having stable sleep cycles, which means having sleeping and waking times that are similar day in and day out
- Storing energy for play
- Looking and listening
- Paying attention
- Learning about the world
- Being able to pay attention to important things in the environment and ignore things that aren't as important
- Being a social partner with a caregiver

Babies work hard in the first months after birth to sleep, wake up, and stay awake both at the same time and for the same amount of time. They manage to go from drowsiness to light sleep and deep sleep; they also manage to wake up and become alert, although they may be fussy at first. Eventually, they do all of this smoothly. They show that their sleeping and waking times are maturing by waking up for eating as well as by staying asleep even when it is noisy. When they are awake they begin to learn by looking at their parents' and other people's faces, listening to voices, and taking in the world.

Remember, when babies are put down for sleep, they need to be on their backs, not on their tummies even if that's how they slept in the hospital.

Other body movements you might have heard about that babies do are called reflexes. Reflexes are responses of the baby when they are touched or stroked on a part of their body. For example, when the baby's cheek is touched or stroked, the baby's mouth moves in that direction. Another example is when either the palm of the hand or under the toes is touched, the baby will grasp with their fingers or toes. There are other terms or definitions you may have heard that describe movement. Tone is a word that refers to the body's being either limp or floppy, stiff or relaxed. Words like "hypotonic" (limp) or "hypertonic" (stiff) are sometimes used to describe a baby's tone. Posture is another term used to talk about body movement. Posture is how the baby's body is when at rest and when handled. Words like "flexed" (bent) or "extended" (stretched out) are sometimes used to describe a baby's posture. Sometimes babies also have movements that are described as tremors, startles, and twitches. Tremors are quick repeating movements and can be seen in the face, tongue, arms, hands, legs, or feet. Twitches are usually just one or two sudden fast movements of each of the body parts, as well as the body. Startles are sudden whole body responses that typically occur with handling or sound but can sometimes happen without any clear reason.

Body Movement

Babies come out of their mother's body, where they were surrounded by fluids, into a world that takes some time to get used to. Over time, babies gradually get better at moving smoothly and without too many supports like being swaddled in a blanket. They become better at snuggling their bodies into the bodies of their parents and caregivers and adjusting themselves to be comfortable.

Babies who are born early, or who spend their first days, weeks, or months in a hospital may move differently or get themselves into body positions that are different from those of typical babies. Sometimes this happens because these babies have not been carried or held as much as babies who were born on time and went home right away. They may have been in bed for long periods of time, or may have had medicines or treatments that affect their movement. These babies may also be especially sensitive to touch and to being moved.

Here are some examples of how you might expect a typical infant to move:

- Stays in a softly bent position most of the time
- Brings his hands together in front of his body
- Keeps his arms and legs tucked into his body most of the time
- Has less jerky movements and more smooth movements
- Begins to reach toward caregivers
- Touches his own head, body, hands, and arms—later feet and legs
- Molds or snuggles into a caregiver's body when held
- Is able to move both sides of his body equally well

When babies have steady body movements, it provides solid building blocks for:

- Snuggling up to mom and dad and other caregivers
- Holding their head steady
- Reaching for parents' faces and then later for objects
- Rolling over
- Sitting

Interactions with People

Being with people is a basic building block for social and emotional development and starts when a baby begins learning her mother's voice and movement patterns before being born. Even the mother's smell and taste of skin and breast milk are known to the baby and help lay a foundation for early attachment. Babies come ready at birth to listen to their parents' voices and look at their faces. They can even imitate their parents' frowns and smiles as if they were having a conversation. Early and regular close and private times between a mother and her baby are important. Through intimate experiences, babies learn to trust that their parents will protect, care for, and love them.

Babies born with medical and developmental concerns may be so sick and not developed enough that they have few good times for interacting with their parents. Their parents, in turn, may not know how to talk to, touch, and hold their baby or feel comfortable doing so. At first, simple touching, holding, and providing mother's smells and tastes of breast milk can help an infant begin to interact. Later, when the baby opens her eyes and can stay awake, her parents can help her build skills and trust by just looking at her quietly. For quite a while after birth some babies are easily overwhelmed by sound and light or when they are moved. In these cases, caregivers need to match their interactions to the baby's energy level, how tired or awake they are, and need for "time-outs."

Here are some examples of how you might expect a typical baby to interact:

- Becomes alert for short periods of time
- Turns her head toward the sound of her parents' voices
- Follows her parents' faces from side to side with eyes and then head
- Changes her facial expression during interactions
- Decreases her arm, leg, and body movement when her parent comes close and talks softly
- Begins to smile at her parents' faces at about 6–8 weeks after due date
- Starts making sounds in her throat and then with her mouth
- Copies facial expressions

- Starts simple turn taking by "talking" to caregivers and then waiting for the caregivers to respond

When babies have steady interactions, it provides solid building blocks for:

- Looking and listening to people
- Paying attention
- Finding sounds and voices by turning their head or following a caregiver with their eyes
- Tracking or following faces and toys with their head and eyes
- Learning cause and effect
- Trusting in people
- Reacting to things that look or sound different from what they expected
- Learning object permanence—that things that disappear from sight still exist
- Having stranger anxiety—they notice the difference between people who take care of them all the time and people they don't know (strangers) and may get upset when strangers try to hold them
- Communicating
- Feeling secure and comfortable
- Developing language



Credit: Joy V. Browne, UCDHSC



Eating

Eating is one of the most complex skills that a baby must master. It develops during the first few weeks and months after birth and requires that babies not only wake up and stay awake but also get milk from the breast or bottle to their tummy (sucking and swallowing) while continuing to breathe. They must also handle being moved and held while interacting with the person who feeds them. When a baby is fed, all of his senses are stimulated in an organized way. Taste, smell, touch, hearing, and vision are all important for successful eating. Feeding also provides a time for the baby to feel close to the person feeding him while his stomach is getting full. That is why it is important for eating times to be enjoyable and predictable.

How feedings go early on may affect how feedings go in the future. Babies who begin their lives in the hospital sometimes don't have typical pleasurable eating experiences. They might have been fed before they were able to manage sucking, swallowing, and breathing, making the eating experience feel overwhelming. Many have had painful things happen to their faces which make them try to avoid anything coming near their mouths. Also, they may have had medical conditions that made eating a hurtful rather than a nurturing experience. Many of the

babies who are born early or who have medical complications at birth struggle to develop pleasurable feeding and go home from the hospital still having eating difficulties.

Here are some examples of how you might expect a typical baby to manage feeding:

- Wakes up to eat at regular times
- Turns head toward a bottle or breast touching his face, opens his mouth, and grasps the nipple
- Shows excitement before eating begins and becomes less excited as he becomes satisfied
- Has steady breathing and color during eating times
- Grasps and explores with his hands while eating
- Has a steady pattern of sucking, swallowing, and breathing while eating
- Looks at his caregiver's face while eating, especially as the feeding progresses into a relaxed interaction
- Becomes relaxed as his tummy fills and may drift off to sleep

When babies have steady early eating experiences, it provides solid building blocks for:

- Growing and gaining weight
- Feeling secure, satisfied, and nurtured
- Eating other foods like strained foods, soft solids when he is older
- Using a spoon and drinking from a cup and sipping from a straw
- Feeding himself
- Having table manners
- Having social interactions while eating

Eating is complex and might help us understand how the baby is developing. Babies gradually develop more sophisticated eating skills over time, but it takes a sensitive caregiver to help them, especially if they were born early or had medical complications around the time of their birth.

Self Soothing

Self soothing is the ability of babies to calm themselves down with less and less help from their caregivers. Other words for this are self regulation. At first, babies need help from their caregiver to both calm down and wake up. Some also need their parents to protect them from loud sounds, bright lights, too much handling, and other activities that overwhelm them. Over time most babies become better able to manage all of this stimulation and soothe themselves. Babies who can calm themselves can also better manage stress when they are uncomfortable, which helps them become steady. Babies show that they are self soothing in many ways, for example when they suck on their hand, brace a foot on the side of the bed, or grasp a blanket.

Babies who are born early or have medical complications at birth may be more sensitive to the environment and may react in many ways. For instance they may become fussy or withdraw. For very sensitive infants, even looking at people's faces and listening to their voices may cause them to look away, change their breathing, go limp, or extend their arms and legs. When babies become overwhelmed, they need their parents or caregivers to step in and help them with their regulation. Many times it will be hard even for caregivers to soothe them. Gradually, over time, caregivers need to help a baby learn to become calm using her own self soothing skills.

Here are some examples of how you might expect a typical infant to self soothe:

- Calms when talked to or given a pacifier
- Brings her hands to her face, head, or mouth
- Braces her feet on the bed, bedding, or the caregiver's hands
- Looks at her parent's face to help herself calm down
- Looks away from faces or objects that are too overwhelming
- Settles herself to sleep on her own when put into her bed

When babies have become good at self soothing, it provides solid building blocks for:

- Looking and listening
- Becoming emotionally steady
- Coping with stressful events and places
- Controlling their own behavior
- Sitting still
- Paying attention
- Learning

Credit: Joy V. Browne, UCDHSC



In order for a baby to be available for learning about her parents, family, and world, she needs to begin to learn to calm herself and be alert for interactions that are typical for infants. The ability to signal what she needs, like being hungry, wet or sleepy, and gradually calming down from crying or fussing, begins to lay the building blocks for adjusting to many situations, places, and people. Caregivers who recognize when their baby is becoming overwhelmed, and know how to begin to help them to use their self soothing skills, can lead their infants to learning to manage the world around them.

What Parents and Caregivers Do and How Early Relationships Develop (PreSTEPS)

- **P**redictability and Continuity
- **S**upport of Self Soothing
- **T**iming and Pacing
- **E**nvironmental Support
- Supportive **P**ositioning, Handling, and Movement
- **S**leeping, Awake Time, and Social Relationships

Babies develop best when they are nurtured by their parents, family members, and close friends. Having a close relationship with your baby means that you are aware of her needs and can respond to them. Each time you are with your baby, you pay attention to her and respond to her special signals. Her behavior gives you clues to how you can change the environment, slow things down or speed things up (change your rhythm), or give her different amounts of support. You also are flexible in how you respond since different things may work at different times. When you respond to your baby each time she needs you, it lets her know that you are always there to support her

development. Parents sometimes worry that if they respond to their baby each time she cries or fusses it might spoil her but that's not true. Babies count on the adults who take care of them to respond each and every time. Responding to babies, holding them a lot, and paying close attention to them does not spoil them—instead, it helps them grow up trusting others to help them become better at soothing themselves.

Through daily contact with the same close circle of caregivers, babies learn to trust others. They also learn what to expect next, how people respond when they signal that they need something, and how good they are at getting their needs met. Over the first few weeks and months after birth you will respond to your baby thousands of times. The interaction you have with your baby will include paying attention to her and responding to her signals. This process will help create the special and highly important relationship you have with your baby.

You can show your baby that you are there to respond to her unique needs in many ways. PreSTEPS stands for the ways that parents and close caregivers help babies and include: Predictability and Continuity (Pre), Support of Self-Soothing (S), Timing and Pacing (T), Environmental Support (E), Positioning, Handling, Supportive Movement (P), and Sleeping, Awake Time and Social Relationships (S). Thinking about PreSTEPS will help remind you of the things you can do each day to support your baby's development.



Predictability and Continuity

Predictability and Continuity describes all of the ways that you keep things the same for your baby and how you create routines that help your baby develop a sense of trust in others. Babies develop best when they have a world that is safe, organized, and consistent. When you create such an environment you teach your baby about what happens next, what to expect, and how to respond to what happens around them.

Things that you can do to create predictability and continuity:

- Prepare your baby for what will happen next by using your voice, your touch, and the way you move. You might tell her with words or use a familiar signal—for example holding the pacifier up for her to see before giving it to her.
- Before you start to do something that is new for your baby you might touch her gently to let her know about the change or simply that you are there.
- Having the same things happen at the same time of day and in the same place also creates a predictable and safe environment for babies. For example, feeding your baby in the same chair, in the same room, at the same times each day helps her know what to expect so that she feels safe and comfortable.
- When you do the same things in the same way over and over again, your baby learns to trust that you will come when she needs you and that you will take care of the things that she needs.
- Letting other people know how to take care of your baby and encouraging them to do it the way you do also helps keep things familiar for your baby.



Dear Family:

Thank you for taking such good care of me. You let me know that something will happen by telling me about it or touching me gently before you start. Even though I'm little, having things happen at the same time each day helps me learn what will happen next. I like my routines and the schedule you have for me. You also make sure that the same few people are with me almost every day. You know what I like and what I don't like, and you tell my likes and dislikes to other people who take care of me and what I might to do in different situations. I like it when everyone who takes care of me does things in the same way.

Dear Family:

Thank you for helping me learn how to keep myself steady. You tell me and other people around me all about the things that I do to keep myself calm. You give me extra support during times when I'm tired or feeling overwhelmed. And you always know what position to put me in to help me use my own skills to stay calm and steady. I love how you offer me your own body, voice, and face so that I know I can do it by myself when I listen to you or look at you and feel the support of your body.



Credit: Joy V. Browne, UCDHSC

Support of Self Soothing

Support of Self Soothing describes how you would help a baby keep himself steady and learn how to calm himself and quiet down, even after being upset. When you help your baby stay calm and steady, he can pay attention to the world around him, learn, and interact with people. At first babies need grown-ups to help them calm down. Eventually, they learn how to calm with less help and how to keep themselves steady.

Things that you can do to support self soothing in your baby:

- Notice the things that your baby already does to keep himself calm and steady. For example, he might be getting his fingers to his mouth, grasping your finger, or looking at your face.
- Think about how good your baby is at keeping himself self calm and steady.
- Know how your baby tries to keep himself calm and steady in situations that are different or overwhelming for him, especially when he is tired.
- Put your baby in positions that will help him to use his own skills to stay calm and steady. For example, swaddle him in blankets with his hands near his face so that he can get his hands to his mouth, or lay him on your lap so that he can push against your body with his feet.
- Use your body, bedding, or other supports to help your baby have successful efforts at calming himself. For example, offer your finger or blanket for him to grasp or give him a pacifier to suck on.
- Use your body, face, and voice to help your baby stay calm and steady. For example, talk softly so that he can hear your voice, or let him look at your face to help him calm down.

Timing and Pacing

Timing and Pacing describes how you pay attention to your baby's reactions and give her a chance to respond to what's happening around her. When the timing of your actions matches what your baby needs, you help to keep your baby's body functions, movement, sleep patterns, and interactions steady. You also help your baby feel more in control when you let her make a response to something that happens around her, notice her response, and then you decide what to do next based on her signals. Your baby has more energy to be involved in what is happening to her when these things happen during awake time. For babies with special health care needs, having too many things happen at once or having things happen when babies aren't expecting them can be especially overwhelming.

Things that you can do to time and pace interactions with your baby:

- Notice how your baby reacts in different situations, like going to the grocery store or being in a noisy room, and see when your baby needs a break. For example, your baby may let you know that she needs a break when her breathing or movements become less steady, or when her color changes. She may also need a break when she yawns, hiccoughs, fusses, cries, looks away, or suddenly falls asleep.
- Do things when your baby is ready for them to be done, like feeding your baby only when she is fully awake, or letting her sleep even if it is her usual bath time.
- Slow things down if your baby shows you that she is having a hard time, for example, by breathing harder, looking away, starting to fuss—or go a little faster if your baby is ready for it. For example, if she looks away when you talk to her, stop talking until she looks back at your face, or if she starts to look at you, talk softly to see how she responds.
- Give your baby a chance to respond to the changes you make before making other changes. For example, let her breathing even out and become more steady after a diaper change before picking her up, or pause a feeding if she starts to go limp.



Dear Family:

Thank you for being there for me. You interact with me when I am fully awake and ready to play. When we are together, you watch me carefully and give me a chance to respond to you before doing something else. You pay attention to how I act and slow things down when I get overwhelmed. You give me a chance to catch my breath. If I don't need to have something done right away, you let me sleep when I'm tired and wait to do it until I wake up. You also figure out when the best times are to do things like eating, playing, and taking baths. When you are getting ready to leave me, you do it slowly and carefully so that I stay steady and calm. And even when you are finished with what you need to do, you stay with me until you are sure that I am ready for whatever is next.

Dear Family:

Thank you for creating an environment that is dim, quiet, and soothing, and not busy for me to rest in. You always make changes when I need you to, like when a bright light is shining at my face or when the television is too loud. When I am awake and ready to play, you give me wonderful things to look at. I especially love looking at your faces. If I am sleepy, you quiet yourself down and let me get some rest. You also notice and help other people notice how I am affected by things around me. And, you try really hard not to take me around to too many busy places or be cared for by too many other people.



Environmental Support

Environmental Support describes how a baby's surroundings can affect him whether he is sleeping, playing, or interacting with people, or during any other activity. When you pay attention to how sound, light, and activity affect your baby, you can tell what kinds of situations your baby will do best in. You have probably noticed that your baby likes quiet, soothing environments. Depending on how the surroundings affect your baby, you can make changes to help keep your baby steady and safe.

Things that you can do to provide environmental support for your baby:

- Notice how your baby responds to things around him. He may react to loud noises, bright light, or get overwhelmed with too much activity around him. You might notice that he startles, pauses in his breathing, becomes fussy or goes to sleep when the environment is too overwhelming for him.
- Notice how your baby responds when you make changes to his surroundings. Your baby may open his eyes if you dim the lights or he may eat really well when you find a quieter place to feed him.
- Prepare ahead of time—get things ready for the activities that you have planned so that you and your baby have everything that you need nearby.
- When your baby shows signs of being overwhelmed, help create a calm and soothing environment by decreasing noise, light, and activity levels.
- Going to loud, bright or very “busy” places like grocery stores or amusement parks might be too much for your baby to manage. Think about how he might be cared for at home by a familiar caregiver when these trips are planned.

Supportive Positioning, Handling, and Movement

Supportive Positioning, Handling, and Movement helps caregivers understand how babies respond to being touched and having their bodies moved around. When you know how your baby likes to be touched, you can make changes that help support her development of steady body movement. When babies are moved, they can sometimes become unsteady. They might change the way they breathe, wake up or fall asleep suddenly, or react with stiffness or limpness. Providing your baby with support during movement or touch helps keep your baby steady in many of those basic building block areas.

Things that you do to support positioning, handling, and movement for your baby:

- Keep your baby in a tucked, softly bent position with her arms and legs close to her body, especially when she is being moved and when you are settling her in.
- Move your baby when she shows that she is steady and ready to be moved. Move her slowly and give her a chance to react to the movement before continuing.
- Take turns with your baby, wait for her response and support her to stay steady while you are moving or touching her.
- Use blankets or your body to help keep your baby in a softly bent position. Before your baby goes to sleep, remove any blankets, toys, or other objects from her bed*.
- Be sure to use an approved car seat that is right for your baby's size. Place the car seat in the back seat of your car when taking your baby out for a ride and be sure to follow the manufacturer's directions for installing and using the car seat. Ask your doctor or home healthcare provider if you have questions about how to transport your baby.
- When your baby is awake, offer a variety of positions. For example, place her in your arms, up on your shoulder, or on her back, sides, or tummy. Being in a different position promotes body movement and posture development.

****Be sure that when you put your baby down for naps or at night that you position her on her back for sleep.***



Credit: Joy V. Browne, UCDHSC

Dear Family:

I love when you hold and touch me. Your gentle hands and your supportive body help me feel safe and steady. When you keep me tucked in I feel really cozy. You take the time to move me slowly and carefully, moving my head and my body at the same time and using your own body to support me. Whether you hold me up against your skin or wrap me in a blanket and hold me close, your touch means so much to me. You wait for me to let you know how things feel before going on. And when you can't hold me anymore, you tuck me in so that my body feels really comfortable. When you put me down to sleep you make sure that I'm on my back so that I'm safe and can sleep soundly. You also make sure that I'm safely tucked in my car seat when we go out for a ride.



Dear Family:

I love opening my eyes and seeing your smiling faces looking at me. Thank you for noticing when I am awake and being ready to play with me. You give me breaks when I need them and don't do too many things at once so that I don't get overwhelmed. I like it that you protect my sleep and wait until I'm awake to do things like changing my diaper. When I am awake, you talk to me, smile, laugh, and play. If I start getting upset, you let me know everything is going to be okay and help me get calm again.

Sleeping, Awake Time, and Social Relationships

Sleeping, Awake Time, and Social Relationships describes how and when babies are available to interact with their environment. Babies learn by interacting with people and the world around them. For weeks after they are born they are still developing good sleep habits and smooth transitions from sleep to waking. How do you know when your baby is ready to play? Ready to sleep? What happens when your baby looks at you and smiles, or makes little noises and responds when you make them too? What signals does your baby use to tell you that he isn't ready for interaction? All of these questions have to do with your baby's daily cycles including when he wakes up, when he sleeps, how much energy he has for interacting with people, and how he learns by looking and listening.

Things that you do to support your baby's sleep and awake times and encourage interacting with people:

- Notice if your baby is asleep or awake, tired or ready to play.
- Notice how your baby's behavior changes between asleep and awake. Is it gradual or very sudden? Does it take your baby a long time to wake up? Does he wake up in time for important activities like eating? When you know your baby's patterns and routines, you can find the right time to interact with your baby.
- Provide a quiet, dimly lit space for your baby to sleep in. Keep noise and activity levels down.
- Interact with your baby when he is awake and comfortable, including doing things like changing his diaper and giving him a bath.
- Give your baby things to look at and listen to—the best thing for your baby to see and hear is your face and voice.
- Be patient with how long it takes for your baby's sleep and awake times to become predictable. Babies can take weeks and months to sleep through the night or have longer periods of awake times for play, especially if they were born early or had lots of medical complications.

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Credit: Joy V. Browne, UCDHSC

Resources for Caregivers

Books/Booklets

- *Early Arrivals* by ZERO TO THREE: National Center for Infants, Toddlers and their Families
- *The Magic of Everyday Moments* by ZERO TO THREE: National Center for Infants, Toddlers and their Families
- *Your Premature Baby and Child* by Amy Tracy and Dianne Maroney
- *Parenting Your Premature Baby and Child: The Emotional Journey* by Deborah Davis and Mara Tesler Stein
- *The Scientist in the Crib* by Allison Gopnik and Andrew Meltzoff
- *Touchpoints* by Berry Brazelton

Web Sites

- Early Intervention Colorado
<http://www.eicolorado.org>
- *Getting to Know Your Baby* by Kathleen VandenBerg, Joy Browne, Linda Perez, and Amanda Newstetter. Available at
<http://www.uchsc.edu/cfii/Documents/Getting%20to%20Know%20Your%20Baby.pdf>
- March of Dimes
<http://www.marchofdimes.com>
- National Early Childhood Technical Assistance Center
<http://www.nectac.org>
- Zero to Three
<http://www.zerotothree.org>







Early Intervention Colorado
for Infants, Toddlers & Families

For more information about
Colorado's early intervention system, call

1-888-777-4041

or visit

www.eicolorado.org



Colorado Department of Human Services

people who help people

How to Make Reading Part of Your Child's Life

Parents can make reading with their children an important part of their daily routine. Following are helpful suggestions for reading with young children and choosing appropriate books, including a list of recommended titles.

Tips for Reading with Children

Read aloud to your child every day. From birth to six months, your baby probably won't understand what you are reading. But that's okay! Your baby will get used to the sound of your voice and will also become accustomed to seeing and touching books.

To start, use board books with no words or just a few words. Point to the colors and the pictures and say their names. Simple books can teach children things that will later help them learn to read. For example, they learn about the structure of language – that there are spaces between words and that the print goes from left to right.

Tell stories. Encourage your child to ask questions and talk about the story. Ask your child to predict what will come next. Point to things in books that they can relate to in their own life, like: “Look at the picture of the penguin. Do you remember the penguin we saw at the zoo?”

Buy a children's dictionary. If possible, find one that has pictures next to the words. Then start a “Let's look it up!” habit.

Make writing materials available. Drawing and writing are part of literacy skills.

Visit the public library often. Begin weekly trips to the library when your child is very young. See that your child gets his or her own library card as soon as possible. Many libraries issue cards to children as soon as they can print their own names.

Read yourself. What you do sets an example for your child.

This publication was developed in part with funding from the Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB)/Division of Services for Children with Special Health Care Needs (DSCSHN) through Grant# H84MC07942

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Recommended Book List

Ages 6 – 12 mos.

Baby's ABC
 Baby's World Series
 Babyfaces
 Duck (bath book)
 Eat!
 Farm Animals
 Fish (bath book)
 Food
 Good Night, Baby!
 Mama Mama
 Papa Papa
 Smile!
 Sweet Dreams
 Tough Machines
 Tug Boat (bath book)

Ages 12 – 18 mos.

Black On White
 Counting Farm
 How Many?
 Rainforest Colors
 Speedy Machines
 Trains
 Where is the Baby?
 Where is the Kitten?
 Zoom City

Ages 18 – 24 mos.

A Child's Good Night Book
 Baby Coyote Counts
 Baby Gecko's Colors
 DK's Baby Fun Series
 DK's Baby Genius Series
 Go to Bed!
 Goodnight Moon
 Hug!
 Jamberry
 Little Critter: All By Myself
 Read to Your Bunny
 Red, Blue, Yellow Shoe
 Truck

Ages 24 – 36 mos.

ABC Book
 Big and Noisy
 Black and White Rabbit's
 Brown Rabbit's Shape
 Book
 Bunny My Honey
 Cheerios Counting Book
 Sheep in a Jeep
 Dr. Seuss: The Foot Book
 Follow Me!
 Have You Seen My
 Duckling?
 Hiccup!
 I Heard, Said the Bird
 I Spy
 I Know a Rhino
 Jump, Frog, Jump!
 Let's Go!
 Mouse Paint
 One Stuck Duck
 Over In the Garden
 The Best Mouse Cookie
 The Big Red Barn
 What Is That?

Ages 36-48 mos.

Bugs for Lunch
 Building Machines
 Can't You Sleep Little
 Bear?
 Chicka Chicka Boom
 Boom
 Click Clack Moo
 Clifford the Big Red Dog
 Courdory
 Daddy Calls Me Man
 Elmer
 Farmer McPeeper and His
 Missing Milk Cows
 Good Job Little Bear!
 How Do Dinosaurs Say
 Goodnight?
 I Howl I Growl

I Went Walking
 If You Give A Mouse a
 Cookie
 In the Small, Small Pond
 Just the Two of Us
 Let's Go Visiting
 Paddinton's ABC's
 Pancakes
 Pete's Pizza
 So Many Bunnies
 Ten, Nine, Eight
 The Three Billy Goats
 Gruff
 Where's My Teddy?

Ages 48 – 60 mos.

Alexander and the Terrible
 Horrible No Good Very
 Bad Day
 Blastoff ABC
 Borrequita and the Coyote
 A Chair for My Mother
 Creepy Creatures
 Custard the Dragon
 Edward the Emu
 From Seed to Plant
 Green Eggs and Ham
 Growing Frogs
 Growing Vegetable Soup
 Hooway for Wodney Wat
 I'll Love You Forever
 Jack and the Giant
 Lyle, Lyle Crocodile
 Mamma Do You Love Me?
 Old Jake's Shirts
 Tacky the Penguin
 The Cat In the Hat
 The Seals on the Bus
 The Ugly Vegetables
 The Velveteen Rabbit
 Too Many Tamales
 Where the Wild Things Are
 Winter
 Wonderful Worms

Appendix



This section includes miscellaneous information that may be helpful to parents. It includes a list of commonly used abbreviations, a description of healthcare specialists, and a glossary with definitions.

Health Care Providers by Specialty

Blood

Hematologist
Phlebotomist

Bones and Joints

Orthopedist
Orthopedic Surgeon
Physiatrist
Rheumatologist
Sports Medicine Specialist

Breastfeeding

Obstetrician / Gynecologist
Lactation Consultant

Cancer Care

Oncologist

Case Management

Social Worker
Care Coordinator
Case Manager

Complementary and Alternative Medicine

Medical Doctor
Osteopathic Doctor
Chiropractor
Acupuncturist
Homeopath
Herbalist

Critical / Intensive Care

Critical Care Specialist
Intensivist
Nurse Practitioner

Diet / Nutrition

Gastroenterologist
Dietician
Nutritionist

Ears, Nose & Throat Hearing & Speech

Otolaryngologist (ORL)
Audiologist
Speech & Language Therapist

Emergency

Emergency Physicians
Emergency Medical Technician (EMT)
Paramedic

Eyes / Vision

Ophthalmologist
Optometrist

Foot Care

Podiatrist
Orthotists
Prosthetist

Genes

Geneticist
Genetic Counselor

Head / Neck / Back

Orthopedist
Physiatrist
Chiropractor
Physical Therapist
Orthotist

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Health Care Providers by Specialty

Heart

Cardiologist

Neurosurgeon

Occupational Therapist

Hormones and Glands

Endocrinologist

Newborn Babies

Neonatologist

Immune System

Immunologist

Allergist

Infectious Disease Specialist

Pain Management

Anesthesiologist

Rheumatologist

Palliative Care Specialist

Neuro Psychiatrist

Acupuncturist

Hospice Nurse

Kidney

Nephrologist

Rehabilitation

Physiatrist

Rehabilitation Medicine Specialist

Physical Therapist

Occupational Therapist

Orthotist / Prosthetist

Exercise Physiologist

Speech Pathologist

Lungs

Pulmonologist

Pulmonary Specialist

Respiratory Therapist

Medical Imaging (x-rays, CT, PET, and MRI scans)

Radiologist

X-Ray Technician

Reproductive Health (female)

Gynecologist

Obstetrician

Nurse Midwife

Mental, Emotional, or Behavioral Health

Psychiatrist

Neuropsychiatrist

Behavioral Neurologist

Clinical Social Worker

Counselor / Therapist

Reproductive Health (male)

Urologist

Muscles

Rheumatologist

Physiatrist

Physical Therapist

Skin

Dermatologist

Plastic Surgeon

Nervous System

Neurologist

Neuropsychiatrist

Stomach, Colon, Intestines, and Abdominal Organs

Gastroenterologist (also called GI Specialist)

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Health Care Providers by Specialty

Surgery

Surgeon
Anesthesiologist
Nurse Anesthetist

Teeth and Gums

Dentist
Orthodontist
Periodontist
Oral Surgeon
Dental hygienist

Urinary Tract

Urologist

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Glossary

Accommodation	Service, provision, or adaptation to meet a specific need. In special education, accommodation refers to the types of services offered to a child so that he or she can fully participate in school.
Acute	A condition beginning abruptly with sharp or severe intensity, then subsiding shortly after.
Acute Care Hospital	A hospital that provides a full range of medical care, usually over the short-term, for sickness or injury.
Advocacy	Speaking up or taking action for a person, a group or belief. An advocate may help family resolve problems with a school system or a health insurance plan.
Affiliation	Membership in a group or plan. A primary care provider (PCP) may be affiliated with a hospital and a health insurance plan.
Americans with Disabilities Act (ADA)	A Federal law that protects the rights of people with disabilities from discrimination in any public program, service, or building.
Attention Deficit Hyperactivity Disorder (ADHD or ADD)	A syndrome of learning and behavioral problems that is not caused by any serious underlying physical or mental disorder and is characterized by difficulty in sustaining attention, by impulsive behavior (as in speaking out of turn), and usually by excessive activity.
Anaphylactic Shock	A severe, sometimes fatal systemic hypersensitivity reaction to a substance, drug, vaccine, food, serum, allergen, venom or chemical.
Anemia	A decrease in hemoglobin in the blood levels to below normal range.
Anesthesiologist	A physician specializing in anesthesiology (pain control and surgery sleep).
Apgar Score	A score to rate the health and strength of a baby right after birth. It measures heart rate, breathing, color, muscle tone, and reflexes on a scale from 1 to 10.
Apnea	Abnormal periods when breathing stops.
Appeal	To formally ask or request that a decision be reviewed.
Arnold-Chiari Malformation	A herniation of the brain stem and lower cerebellum through the foramen magnum into the cervical vertebral canal often associated with hydrocephalus and spina bifida.
Arterial	Of or pertaining to an artery (leads to the heart).
Assessment	The formal process used by expert professionals to learn about a person's strengths and needs. An assessment can also be called an evaluation. Assessment results are used to recommend treatments or develop care plans. Sometimes an assessment or evaluation is used to determine whether a person is eligible for a service or benefit.
Assistive Technology (AT)	Any kind of tool or piece of equipment that helps a person live more independently. AT can be high-tech or low-tech.

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Asthma	Recurring attacks of breathlessness, characteristically accompanied by wheezing when breathing out and varying in severity from day to day.
Attending Physician	The main doctor who is responsible for care and an experienced doctor who supervises a medical team.
Audiological Evaluation	Hearing screening/testing.
Autism	A mental disorder originating in infancy, characterized by self-absorption, inability to interact socially, repetitive behavior, extreme withdrawal, abnormal fantasy absorption, and language dysfunction (echolalia).
AzEIP	Arizona Early Intervention Program, which provides coordinated service to eligible children, birth to 3 years of age and their families.
Baseline	A starting point used to compare observation or data. Baseline physical findings are the results from a first medical exam. Baseline vitals include regular heart rate (pulse), blood pressure, respiratory rate (breathing rate), and body temperature. Baseline neurological status is an assessment of development, cognition, motor skills, and mental health. Baseline Ancillary findings are any other important issues.
Benign	Of a tumor, mild type with no immediate threat may require future treatment.
Birth to Three Program(s)	A program of services for children between birth and three who currently have a developmental delay.
Blood Gas	A test determining the pH and concentrations of oxygen, carbon dioxide, nitrogen, and bicarbonate in the blood.
Blood Sugars	The concentration of glucose in the blood.
Bowel Sounds	A rumbling sound made by the movement of gas in the intestine.
Bronchopulmonary Dysplasia (BPD)	A chronic lung condition that is caused by tissue damage to the lungs, marked by inflammation, exudates (substance discharged from), scarring, fibrosis, emphysema, usually occurring in immature infant who have received mechanical ventilation and/or supplemental oxygen as treatment for respiratory distress syndrome.
Bradycardia	An abnormal circulatory condition where the heart rate drops below 60 (beats) contractions per minute.
Broviac / Central Line	A long-term central venous catheter (tiny, flexible rubber or silicone tube) threaded through the chest into a large vein leading to the heart.
Cardiologist	A doctor who specializes in the diseases of the heart and blood vessels.
Cardiovascular	The system which includes the heart and blood vessels.
Center-Based Services	Early intervention services provided at a "Center" - not in the family home.
Cerebral Palsy (CP)	A condition caused by injury to the parts of the brain that control the ability to use our muscles and bodies.
Cerebrospinal Fluid (CSF)	The fluid that flows through and protects the ventricles, brain, and spinal canal.

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Cerebrovascular Accident (CVA)	Abnormal condition of blood vessels of the brain; resulting in decreased brain tissue normally perfused by the damaged vessels.
Children with Special Health Care Needs (CSHCN)	Children with special health care needs (CSHCN) are those from birth to 21 years old who have, or are at increased risk for, chronic physical, developmental, behavioral or emotional conditions. Generally these children also need more health and related services than most children.
Chronic	A condition developing slowly and persisting for a long period of time (often lifetime condition).
Circulation	The movement of blood through the vessels of the body that is induced by the pumping action of the heart and serves to distribute nutrients and oxygen to and remove waste products from all part of the body.
Cleft	Divided; a fissure usually originating in embryo.
Cognition / Cognitive	The mental process characterized by knowing, thinking, learning, and judging.
Colitis	Inflammation of the colon (large intestine) causing diarrhea, usually with blood and mucus.
Collaboration	The establishment and maintenance of open, cooperative communication and working relationships among families and service providers in identifying goals and delivering care to individuals.
Colostomy	Surgical formation of an artificial anus by connecting the colon to an opening in the abdominal wall.
Community Based Care	Services delivered locally, or as close to the home as possible. This type of care helps individuals participate fully in all aspects of family and community life.
Congenital	Present at, or existing from the time of birth.
Contractures	Deformity caused by shrinkage of scar tissue, connective tissues, or shortening of the muscles and tendons.
Continuous Positive Airway Pressure (CPAP)	In respiratory therapy; ventilation assisted by a constant air flow delivered throughout the respiratory cycle.
Chest Percussion Therapy (CPT)	Systematic pounding on the chest in order to loosen chest congestion.
Culturally Sensitive	Care that is responsive to the values, beliefs, social norms and behaviors of the individuals or population being served. Recognition of the values of different population groups.
Dehydration	An excessive loss of water from the body tissues.
Depth Perception	Ability to judge the distance of objects in spatial relationship to one's position.

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Developmental Delay	This term refers to when a child does not reach developmental milestones (such as walking and talking) within the same time range as most other children. Developmental delays may be generalized (all milestones), or they may show up in just one or two milestones. Developmental disability usually refers to a general delay, and to chronic conditions appearing in childhood which result from mental or physical impairment. Often this means major and life-long limitations in everyday functioning.
Developmental Specialist / Early Intervention Specialist	Focuses on the educational aspects of care; carries out recommendations given by therapists; assists in identifying the family's strengths and needs; is not a therapist.
Diagnosis	The definition of a condition or illness.
Dietary Supplements	Extra calories, vitamins, minerals, proteins, or other nutrients. Usually taken in the form of pills, powders, or drinks. Also called dietary additives.
Discharge Plan	A plan created by a hospital team of providers before it's time to leave the hospital (such as appointments to see health care providers, plans for home health nursing, assessment for durable medical equipment).
Do Not Resuscitate (DNR) / No Code	A written order by a qualified physician instructing not to attempt to resuscitate a particular patient in the event of cardiac or respiratory failure; usually only written for patients that are gravely ill, death is imminent, or death inevitable.
Diagnosis	Identification of a disease or condition by scientific evaluation.
Distended	To be swollen from a force within.
Due Process	Due process is an important element of the state and federal legal systems. It gives the legal right to be notified and to be heard of certain benefits or services are denied. For example, there are regulations that make sure that parents can challenge a state's decisions about their children's eligibility for early intervention or special education services.
Durable Medical Equipment	Supplies or equipment that last a long time and help meet particular medical needs.
Dyslexia	Reading disability or difficulty in coping with written symbols.
Early Intervention	Educational and other services provided to families with infants and toddlers, birth through two years of age, who have developmental delays or physical problems which may cause delays.
Edema	Any abnormal accumulation of fluid; swelling.
Elective Procedures	A medical test, procedure, or surgery that is not an emergency. Usually a person or doctor decided and plan the procedure together in advance.
Eligible	Meeting certain requirements for getting services or benefits.
Elimination	Bodily discharges including urine, feces, and vomit.
Embolism	The obstruction of a blood vessel by a foreign object (e.g.: air, gas, tissue, tumor).

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Emergency Information Form for Children with Special Needs	The form is filled out by a child's primary care provider (PCP) and gives emergency providers the information they need to properly care for a child.
Emergency Response Plan	An emergency plan created by families and their child's primary care provider. An Emergency Response Plan includes: medical information about the child, the name(s) of the child's PCP and other important providers, where the child should be taken in an emergency, and treatment that should be provided to the child in the certain situations.
Emesis	Medical term for vomit.
Entitlement	A service or benefit that an eligible person has a right to receive.
Epilepsy	A neurological disorder characterized by recurrent seizures; uncontrolled electrical discharge from the nerve cells of the cerebral cortex (in the brain).
Evaluation	In medicine, and evaluation is a checkup, a study, or a series of tests used to determine the current status of a patient or a particular condition. An evaluation may also refer to the process used to determine whether or not a child is eligible for a service or benefit. A way of collecting information about a child's needs, strengths, and interests.
Extremity	A limb of the body; especially a human hand or foot.
Family-Based Services	Early Intervention services provided in the family home.
Family-Centered Care	Care that recognizes the family as the most central and important influences in the child's life. In family-centered care, the provider makes sure that the family participates in all health care decisions about the child. Family-centered care is one of the key elements of Medical Home.
Family Support Services	Service to meet the needs of family members. Examples include: respite care, parent networks, equipment exchanges, advocacy services, support groups, information and training, and any other assistance that enhances family life and participation in the community.
Febrile	Feverish or related to fever or rise in normal body temperature.
Fissure	A cleft or groove on the surface of an organ.
Fistula	An abnormal passage from an internal organ to body surface or between two internal organs.
Flaccid	Weak, soft, flabby; lacking normal muscle tone.
Flight or Fight Reaction	A physiological or psychological reaction of the body to stress.
Fontanels / Fontanel	One of the two soft areas on a baby's scalps a membrane-covered gap between the bones of the skull.
Fusion	Bringing together into a single entity; uniting two or more bones.
Gag Reflex	A normal neural reflex elicited by touching the soft palate or back of the tongue.
Gastroenterologist	A doctor who specializes in the diseases of the digestive system, including the liver.

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Gastrointestinal	Part of digestive system that consists of the mouth, esophagus, stomach, intestine, and anus.
Gastronomy Tube (G-Tube)	A latex or plastic tube inserted in a surgical opening in the stomach to provide nourishment.
Genetic	A trait that is hereditary, "runs in the family", passed down, or affected by genes. Genetic counseling is when a trained genetic counselor educates and counsels families about inherited genetic disorders.
Geneticist	A doctor who specializes in conditions that are genetically based or which are hereditary.
Gestation	The time that a baby is carried in the uterus during pregnancy. Babies are expected to be born after 10 months or 40 weeks gestation. A premature baby is born before 37 weeks gestation.
Grievance	A complaint about or dissatisfaction with a service or benefit.
Guardianship	Guardianship is a court process and legally binding. It makes an adult (or adults) legally responsible for the personal and financial decisions of a person who is unable to make these decisions alone. A guardian may or may not be a relative. Parental rights may or may not be terminated. Guardianship can be temporary or permanent, partial or complete.
Habilitation	Procedures and interventions designed to assist the individual to greater mental, physical and social development.
Health Care Provider	Any professional who provides a health care service (such as a doctor, nurse, or therapist).
Health Care Team	An interdisciplinary group of family members and professionals who collaborate in planning, delivering and evaluating health care services for an individual child with special health care needs.
Health Insurance	A type of insurance that pays for covered health care costs. Primary health insurance is the main plan that covers most health care costs. Secondary insurance is the additional insurance that covers costs not paid for by the primary health insurance plan.
Health Treatment Plan	A written plan of services and therapeutic interventions based on a comprehensive assessment of an individual child's developmental and health status, strengths, and needs that is designed and periodically updated by the health care team.
Hemiparesis	Muscular weakness or partial paralysis affecting one side of the body only.
Hemoglobin	The oxygen carrying pigment found in the red blood cells carries oxygen to lungs and other body tissues.
Hemorrhage	A rapid loss of a large amount of blood externally or internally.
Hereditary	Pertaining to a characteristic, condition, or disease transmitted from the parent.
Hernia	Protrusion of an organ through an abnormal opening in the muscle wall.

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Home Health Aide	A professional who provide home care services, including: personal care services; simple dressing changes or help with medications that do not require the skills of a nurse; help with special activities and therapies; and routine care of prosthetic and orthotic devices.
Hospice Care	The special kind of health care focused on life-limiting illness. It can be provided in the home and outside of the home in hospitals or hospice centers. Hospice care may include any of the home health services, but also usually includes both counseling services and palliative care nursing. Palliative care is focused on preserving patient comfort and dignity in the face of terminal disease.
Hydrocephalus	Abnormal accumulation of CSF in the ventricles with increased pressure.
Hyper-	Combining form meaning: excessive, above or beyond.
Hypo-	Combining form meaning: under, beneath, or deficient.
Hypoglycemia	Low level of glucose in the blood.
Hypotonia	Excessive limpness in any body part.
Ileostomy	Surgical formation of an artificial anus by connecting the ileum to an opening in the abdominal wall, through which fecal matter is emptied.
Immunization	A process that helps the body resist or overcome infectious disease. A substance (usually given in the form of a shot) that protects a person from viruses and bacteria. Also called a vaccine.
Immunosuppressed	When the immune system is inhibited to responding appropriately.
Impairment	An injury, deficit, or disability.
Inclusion	In the schools, inclusion or inclusive education means that all children learn together in the same schools and classrooms. Services and supports for children with special needs are built into regular school and classroom activities.
Individualized Education Plan (IEP)	A special education service plan for a child's school program. It is required by law for all children receiving special education services. An IEP describes an individual child's educational goals, and any services or help the child needs to meet these goals.
Individualized Family Service Plan (IFSP)	A care plan required by law for every child enrolled in Birth to Three (Early Intervention) programs.
Individualized Health care Plan (IHCP)	A care plan designed to manage the medical care of a child with special health care needs in school.
Individuals with Disabilities Act (IDEA)	The Individuals with Disabilities Education Act is the federal special education law.
Input	Amount of fluids put into the body.
Insulin	A hormone that regulates the level of glucose in the blood.
Interagency Collaboration	Cooperative efforts between or among agencies to maximize resources on behalf of children with special health care needs and their families.
Intellectual Disability	Sub-average intellectual ability that is equivalent to or less than an IQ of 70, occurs during the developmental period, and is manifested especially by abnormal development, cognitive impairment, and problems in social adjustment.
Intubation	Passage of a breathing tube to ensure an airway.

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Intuition	Direct apprehension about truth without reasoning.
Irritability	Showing signs of being fretful, fussy, touchy and sensitive.
Jejunum Tube (J-Tube)	Artificial opening made through the abdomen into the jejunum (part of the small intestine) where a small latex or plastic tube is placed to provide nourishment.
Juvenile Diabetes	An inability to metabolize carbohydrate caused by an overt insulin deficiency; occurring rapidly in children, eventually leading to a dependency on insulin.
Ketoacidosis	Complication of diabetes an accumulation of ketones in the body.
Laceration	A torn and ragged wound.
Latent	Dormant; exists as a potential, can become active under certain conditions.
Least Restrictive Environment (LRE)	A term that means that a child should be educated in the same classroom and school as he or she would be in if he or she did not have any disabilities.
Lethargy	The state or quality of being indifferent, apathetic or sluggish.
Local	Of or pertaining to a small circumscribed area of the body.
Mainstreaming	Programs and policies to include people with disabilities in regular programs and services, such as education. See inclusion.
Malignant	Tending to infiltrate, metastasize, become worse or cause death.
Mandate	Something that is required by law. For example, free public education is a mandate.
Medical Emergency	A serious medical condition that results from injury, sickness or mental illness, which is sudden and severe and requires immediate treatment.
Medical Home	Medical Home is an idea that promotes a coordinated system of care that is accessible, continuous, comprehensive, family centered, compassionate, and culturally effective. The primary care provider shares responsibility to ensure that the child receives this kind of care.
Medical Necessity	Standards of medical practice that health plans use to make decisions about the coverage of special services or equipment.
Meningitis	Any infection or inflammation of the membranes covering brain or spinal cord.
Mental Status	The awareness of current status, pain, anxiety, depression.
Metabolic	Of or pertaining to metabolism (all chemical processes in living organisms).
Mobility	The ability to move independently.
Musculoskeletal	Involving all muscles and bones in the human body.
Myelomeningocele	Spina bifida: developmental defect of the central nervous system in which a hernial sac containing a portion of the spinal cord, its meninges (membranes), and CSF through a congenital cleft in the spinal column.

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Nasogastric Tube (Ng-Tube)	Tube passed in through the nose to the stomach to provide nourishment.
Natural Environments	To the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural settings, including the home and community settings in which children without disabilities participate.
Nebulizer	A device to produce a fine aerosol spray for dispersing liquid (saline, albuterol,).
Necrosis	Localized tissue death.
Needs Assessment	The process of identifying and documenting strengths and unmet assessment needs and goals in services for children with special needs. Information is gathered from families, providers, and service agencies and may be aggregated on a community, regional or state level. Indicators of the health status of children and service utilization measures are monitored as part of a comprehensive needs assessment process.
Neurologist	A doctor who specializes in the diagnosis and treatment of disorders of the nervous system.
Neurology	The scientific study of the nervous system especially in respect to its structure, functions, abnormalities, and disorders.
Nurse	A nurse provides and coordinates the hands-on treatment and care of a patient. A nurse also assesses symptoms and alerts the doctor to any changes in status by either writing in the medical chart or notifying the doctor immediately.
Nurse Practitioner (NP)	A nurse practitioner is a registered nurse with advanced academic and clinical training that provides primary and specialty medical care. A NP diagnosis and manages most common and many chronic illnesses, either independently or as part of a health care team.
Nystagmus	Involuntary, rhythmic movements of the eyes.
Obturator	A device used to block a passage or canal or filling the space.
Obstruction	A condition of being clogged or blocked.
Occipital	Of or pertaining to the occiput (the back part of the head).
Occupational Therapy (OT)	Treatment to help a person develop mental or physical skills for daily living, especially fine motor skills. Examples include dressing, bathing, writing, and using a fork or spoon. Occupational therapy often involves identifying and learning to use equipment that helps people with these activities.
Ocular	Of or pertaining to the eye.
Ophthalmologist	A branch of medical science dealing with the structure, functions, and diseases of the eye.
Oral	Of or pertaining to the eye.
Ostomy	Surgical procedure where an opening is made to allow passage.
Output	Total amount of fluid removed or emptied from the body.

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Over-the-Counter (OTC) Medicine	Medication that is available without a prescription.
Palliative Care	Care that is provided not to cure, but to keep a patient comfortable. Examples include providing warmth, pain control measures, and appropriate nutrition and medications
Paralysis / Paralyzes	Abnormal condition characterized by loss of muscle function, tone, or sensation.
Parent-to-Parent Support	Parents of children with disabilities providing information and one-on-one support to each other.
Patent	The condition of being open and unblocked.
Peak Flow	To perform peak expiratory flow rate (PEFR) assessments.
Pediatrician	A doctor who specializes in the treatment of children.
Percutaneous	Procedure performed through the skin to aspirate fluid from below the skin.
Peripheral	Of or pertaining to the outside, surface, or surrounding area.
Personal Care Attendant (PCA)	An independent caregiver who helps with the activities of daily living.
Pervasive Developmental Disorder	Children who demonstrate severe impairment in reciprocal social interaction and verbal and nonverbal communication or who show stereotyped behaviors, interests, and activities but who do not meet criteria for autism. Called Pervasive developmental disorder.
Physical Therapy (PT)	Treatment to relieve pain and to improve or restore movement skills and muscle function. Examples of methods of physical therapy include exercise, stretching, massage, heat, cold, water or electrical stimulation therapy.
Physician's Assistant (PA)	A health care provider specially trained to provide medical care under the supervision of a doctor. A PA can conduct physical exams, diagnose and treat illnesses, order and interpret tests, counsel on preventive health care, assist in surgery, and can often write prescriptions.
Pilot Parent Partnerships	A support network for families in Southern Arizona who have children with special health care needs, also providing information and education.
Prescription Drug	Medication that is available only with a written order from a medical provider who is licensed to prescribe medications.
Premature	Happening or arriving before the expected or usual time. A premature baby is usually defined as a baby born at least 3 weeks early, after a gestation period of less than 37 weeks. Sometimes, prematurity means a birth weight of less than 250 grams (About 5 ½ pounds), regardless of gestational age.
Primary Care Provider (PCP)	The term for any professional who provides primary care. A primary care provider (PCP) may be a pediatrician, family physician, specialty physician, nurse practitioner, or physician's assistant.

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Prior Authorization	Also called, prior approval. Getting permission for special services or equipment in advance by the health plan, usually based on medical necessity.
Prognosis	A prediction of the probable outcome of a disease.
Prone	Lying face down on the stomach.
Prophylaxis	A measure taken for the prevention of a disease or condition.
Prosthesis	An artificial device to replace a missing part of the body.
Provider Network	A group of doctors, hospitals, and other health care providers who work together with a health insurance plan to provide health care services.
Psychiatrist	A medical doctor who can counsel about mental health – mood, behavior, and family issues. If needed, a psychiatrist prescribes medications that help with mood or behavior.
Psychologist	A provider, usually with a doctorate in psychology, who can counsel about mental health – mood, behavior, and family issues. A psychologist also does special testing to understand how a child learns, thinks and feels.
Pulmonologist	A doctor who specializes in diseases of the lungs.
Pulse	A rhythmical beating or vibrating movement of blood corresponding to heart beat.
Reactive Airway Disease	Irritant –induced asthma.
Rales	Airflow with abnormal moisture, heard when listening to lungs during inspiration.
Renal	Of or pertaining to the kidney.
Referral	An authorization by a health provider or health insurance plan for a person to receive care (often specialty care) from another provider. Each health plan has its own rules about referrals. Most plans have their own networks of specialists.
Reflux	Abnormal backward flow of fluids.
Rehabilitation	The process of helping a person reach the highest level of function, independence, and quality of life possible.
Respiration	Single complete act of breathing including inhale and exhale.
Respite Care	Care for a limited time, in which a family gets a break from caring for their child with special health care needs. A service that provides temporary care to a child by a trained caregiver. For example, a respite care worker could be another family member, friend, or a professional caregiver. Respite care can take place in out-of-home and in-home settings for any length of time, depending on the needs of the family and available resources.
Resuscitation	Process of sustaining the vital functions during respiratory or cardiac failure.
Retinopathy of Prematurity (ROP)	An ocular disorder sometimes in premature infants occurring when the incomplete vascularized retina completes an abnormal pattern of vascularization that is characterized by the presence of an opaque fibrous membrane behind the lens of each eye.
Retractions	Visible sinking of the soft tissues of the chest area with increased breathing effort.

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Rhonchi	Abnormal sound of airway caused by thick secretions, spasm, or pressure; a rumbling sound more pronounced during expiration that can clear with a cough.
Rigidity	A condition of hardness, stiffness, or inflexibility.
Rupture	A tear or break in an organ or body tissue.
Scoliosis	Lateral curvature of the spine.
Scoliosis Brace	A total contact body shell to prevent progressive spinal deformity.
Screening	The use of basic, standardized procedures to test health, hearing, vision, developmental, behavior, and other factors to identify children with, or at risk of, disabilities or special health care needs.
Second Opinion	An evaluation by a second provider, other than the regular providers. If a health provider gives a new diagnosis or states that a certain treatment or surgery is needed, it is best to find out if another provider agrees with this finding/decision. Most health plans will pay for a second opinion.
Secretions	Releasing some material either functionally specialized (as saliva) or isolate for excretion (as urine).
Section 504	A federal law that protects the rights of people with disabilities from discrimination in programs or activities that receive federal funds.
Sedation	Induced state of quiet, calmness, or sleep by means of hypnosis or medication.
Self Injurious Behavior (SIB)	Causing harm to your own body
Seizure Threshold	The amount of stimulus needed to cause a convulsive seizure.
Septic Shock	Occurs in septicemia when endotoxins are released from bacteria in bloodstream.
Service Support Coordinator	Coordinates and monitors services; advocates for the family; helps identify the family's strengths and needs.
Side-lying	Lying on the side, typically in a fetal position.
Skilled Nursing	Care and treatments by a registered nurse (RN) or a Licensed Practical Nurse (LPN). A nurse can provide teaching and support, perform a skilled procedure, or provide a specific therapy.
Social Worker	An individual, usually with an advanced university degree in social work, who provides counseling and aid to individuals about mental health – mood, behavior, and family issues. A social worker can also help connect individuals to other services within their community.
Speech and Language Therapy (SLT)	Treatment of conditions affecting the voice, speech, swallowing, and written communication. Speech therapy helps children who have language or speech impairments with their communication skills.
Special Pathologist	A specialist who evaluates and treats people with communication and swallowing problems.
Special Education	Special education is specially designed instruction and related services that meet the unique needs of an eligible student with a disability or a specific service need that is necessary to allow the student with a disability to access the general curriculum. The purpose of special education is to allow the student to successfully

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	develop his or her individual educational potential. Special education is free through the public school system.
Special Needs	Individuals with disabilities or chronic illnesses which may require adaptations for daily functioning, prolonged or periodic hospitalizations, or special services in educational settings.
Specialist	A doctor or other health care provider with “special” training in a certain area of medical care.
Specialty Care	Care from a doctor or other health care provider who has special training and experience in treating certain body systems or conditions.
Spina Bifida	A congenital cleft of the spinal column with hernial protrusion of the meninges and sometimes the spinal cord.
Stridor	An abnormal, high-pitched, musical respiratory sound caused by an obstruction.
Suctioning	To remove fluid from a body cavity or passage by suction device.
Supine	Lying face up on the back.
Syndrome	Signs, symptoms, resulting from a common cause, presenting a clinical picture.
Tepid	Moderately warm to the touch
Terminal	A structure or process; near or approaching the end.
Tertiary Care Center	A hospital that provides specialized inpatient and outpatient care.
Text Telephone (TTY)	A TTY, also called TDD (Telecommunications Device for the Deaf), is a special device that lets people who are Deaf, hard of hearing, or speech-impaired use the telephone to communicate, by allowing them to type messages back and forth to one another instead of talking and listening. A TTY is required at both ends of the conversation in order to communicate.
Tidal Volume	Volume of air that passes in and out of the lungs in an ordinary breath and averages 500 cubic centimeters in a normal adult human male.
Title XIX (Title 19)	Grants to states for medical assistance programs. Administered by the Health Care Financing Administration, department of Health and Human Services. Federal Medicaid funding waivers are used to fund mental health and long term care services.
Thermometer	Instrument for measuring temperature.
Topical	Of or pertaining to the surface of the skin.
Total Parenteral Nutrition (TPN)	Nutrition administered by vein or parenteral (not through the digestive system).
Toxicity	The degree to which something is poisonous.
Tracheostomy	An opening (incision) made through the tissue of the neck into the trachea.
Traction	The process of putting a limb, bone, or muscles under tension using weights to align, immobilize, or relieve pressure.
Transfusion	Introduction into the blood stream of whole blood or components of blood.

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Transition	The process of moving from one stage of life or type of service to another. For children with special health care needs, transition usually refers to process of growing older and becoming more independent in areas of health care, employment, living, and recreation. Children in early Intervention (EI) also experience transition when they leave EI and move to school services.
Transplant	To transfer an organ or tissue from one person to another.
Trauma	Physical injury caused by violent action or introduction of toxic substance.
Tremor	Rhythmic, purposeless, quivering moments.
Tumor	A swelling or enlargement occurring in inflammatory conditions.
Ulcer	A crater like lesion of the skin or mucous membrane.
Unconscious	Unaware of surroundings, incapable of responding to sensory stimuli.
Urethra	Small tubular structure that drains urine from the bladder.
Urgent Care	Care given in situations that require immediate treatment but are usually not life-threatening, such as an ear infection, sprained ankle, or flu-like symptoms
Urinary	Of or pertaining to urine or urine formation.
Urticaria	An allergic disorder marked by raised edematous patches of skin or mucous membrane and usually by intense itching and caused by contact with a specific precipitating factor (as a food, drug, or inhalant) either externally or internally.
Uvula	Small, cone-shaped process suspended in the back of the mouth.
Vaccination	Injection of dead microorganisms to induce immunity, reduce effects of disease.
Vascular	Of or pertaining to a blood vessel.
Vendor	A provider, supplier, or seller. For example, a durable medical equipment (DME) vendor is the company that provides equipment.
Ventricle	Small cavity filled with CSF in the brain or the right and left ventricle of the heart.
Ventricle Peritoneal Shunt (VP Shunt)	Silicone tubing with valve device that diverts CSF from the ventricle in the brain to the peritoneal cavity in the abdomen.
Vertigo	Sensation of movement in which the patient feels himself revolving in space.
Voluntary	Pertaining to an action or thought as a result of a person's free will or choice.
Volume	The amount of space occupied by a body, expressed in cubic units.
Well-Baby Care	Periodic health supervision for infants and children in order to promote optimal physical, emotional, and intellectual growth and development.
Wheeze	To breathe with difficulty characterized by a high-pitched musical quality.

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Commonly Used Abbreviations

Abbreviation	Meaning
>	Greater Than
<	Less Than
ACCCI	Arizona Consortium for Children with Chronic Illness
ADD	Attention Deficit Disorder
ADA	Americans with Disabilities Act is a civil rights legislation, which prohibits discrimination in programs and services for individuals with disabilities.
ADE	Arizona Department of Education
ADL	Activities of Daily Living. Term used by some health and home care providers to describe personal care, such as bathing, eating, mobility, simple health care procedures, and occasionally housekeeping activities.
ADHS	Arizona Department of Health Services
ADHD	Attention Deficit with Hyperactivity Disorder
ADL	Activities of Daily Living. Term used by some health care providers to describe personal care, such as bathing, eating, mobility, simple health care procedures, and occasionally, housekeeping activities.
AHCCCS	Arizona Health Care Cost Containment System. Arizona's Medicaid plan for the poor, disabled, and medically needy.
AIDS	Acquired Immune Deficiency Syndrome
ALTCS	Arizona Long Term Care System which is Federally funded to provide medical and therapy services as well as some in-home services for children who qualify; also called Title 19. Also a Medicaid plan to provide services in the community and in certified nursing homes and institutions. Children need not be poor to be in ALTCS.
Arc	Advocates for the Rights of Citizens with Developmental Disabilities and their Families
AT	Assistive Technology
ASDB	Arizona Schools for the Deaf and Blind provides services statewide to sensory-impaired children from birth to twenty-two years of age.
AzEIP	Arizona Early Intervention Program
BAER	Brainstem audio evoked response (also known as ABR)
BIA	Bureau of Indian Affairs
BID	Twice a Day
C	Centigrade
CAT Scan	Computerized Axial Tomography Scan
CBC	Complete Blood Count
CC	Cubic Centimeter
CC/hr	Cc Per Hour
COM	Chronic Otis Media
CP	Cerebral Palsy
CPR	Cardiopulmonary Resuscitation
CPS	Child Protective Services
CRS	Children's Rehabilitative Services, a program under the Arizona Department of Health Services, Office for Children with Special Health Care Needs, provides medical, rehabilitation and related support services for eligible children
CSHCN	Children with Special Health Care Needs

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DD	Developmental Delay
DDD	Department of Developmental Disabilities. Arizona's state agency providing services to developmentally disabled or delayed clients
DES	Department of Economic Security. Arizona's state agency overseeing DDD
DHS	Department of Health Services
DME	Durable Medical Equipment
DNR	Do Not Resuscitate
DO	Doctor of Osteopathy
DOE	Department of Education
DPH	Department of Public Health
DSS	Department of Social Services
ECG or EKG	Electrocardiogram
ED	Effective Dose
EEG	Electroencephalogram
EI	Early Intervention
EIP	Early Intervention Program
EMS	Emergency Medical Services
ENT	Ear, nose and throat doctor who specializes in conditions of the ear, nose and throat
EPSDT	Early Periodic Screening, Diagnosis, and Treatment
FAS / FAE	Fetal Alcohol Syndrome / Fetal Alcohol Effect
F	Fahrenheit
FTT	Failure to Thrive
GI	Gastrointestinal
Gtts	Drops
Gtts/Min	Drops per minute
HCBS	Home and community based services. A list of services available to ALTCS members, in addition to medical care.
HHS	Health and Human Services
HI	Hearing Impaired
HMO	Health Maintenance Organization a medical insurance program which gives care through specified doctors and hospitals
ICC	Interagency Coordinating Council
ICU	Intensive Care Unit
IEP	Individual Education Plan, used for developing special education services in schools.
IDEA	Individuals with Disabilities Act. A public law that allows free and appropriate public education to all children birth through 21 years of age.
IFSP	Individualized Family Service Plan, used when developing a multidisciplinary approach to assisting families who have children with special needs.
IHS	Indian Health Services
IM	Intramuscular
IN	Intranasal
ISP	Individual Support Plan. Created by the Division of Developmental Disabilities
ISPP	Individual Services and Program Plan
IV	Intravenous
IVH	Intraventricular hemorrhage
LD	Learning Disability

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LRE	Least Restrictive Environment. To the maximum extent appropriate, handicapped children including children in public or private institutions or other care facilities are educated with children who are not handicapped. Special classes, separate schooling, or other removal of handicapped children from the regular educational environment occurs only when the nature and severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.
MACDD	Maricopa Advisory Council on Developmental Disabilities
MD	Medical Doctor
MD	Muscular Dystrophy
MET	Multidisciplinary Evaluation Team. A team of medical or educational professionals that evaluate and plan for the evaluation team the health care and / or educational goals for your child
Mg	Milligrams (Strength)
ml	Milliliters (Volume or Amount)
MRI	Magnetic Resonance Imaging
NICP	Newborn Intensive Care Program, part of the Arizona department of Health Services, provides services to infants who are critically ill at birth.
NICU	Neonatal Intensive Care Unit, where babies who are born prematurely or with medical complications stay in the hospital.
Normal Temp.	98.6 or 37C (centigrade)
NP	Nurse Practitioner
NPO	Nothing by Mouth
OCSHCN	Office for Children with Special health Care Needs part of the Arizona Department of Health Services. This office provides services through the Children's Rehabilitative Services, The AZ / Early Intervention Program, Community Development Initiative, and Parent Involvement. Project Tsunami.
ORL	Otolaryngologist (ear, nose and throat doctor)
OSER	Office of Special Education and Rehabilitation Services
OT	Occupational Therapy or Occupational Therapist
OTC	Over the Counter Medicine
PA	Physician's Assistant
PAS	Pre-admission screening. The second part of the ALTCS application which determines the severity of the client's disability. The greater the disability, the higher the amount. A score of 18 is required for ALTC eligibility.
PCA	Personal Care Attendant
PCP	Primary Care Provider or Primary Care Physician
PDD	Pervasive Developmental Disorder
PHS	Public Health Service
PICU	Pediatric Intensive Care Unit
PO	Orally
PRN	As needed or necessary (to treat a symptom)
PT	Physical Therapy or Physical Therapist
PVL	Periventricular leukomalacia
QD	Once a Day
QID	Four Times a Day

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QOD	Every Other Day
R	Rectal
RN	Registered Nurse
Rx	Prescription or Treatment
SC / Sub Q	Subcutaneous
SI	Sensory Integration generally involves therapeutic activities that enhance the senses, such as touch or balance.
SIDS	Sudden Infant Death Syndrome
SLP	Speech Language Pathologist (Therapist)
SSI	Supplemental Security Income. A program for aged, blind or disabled individuals that meet the eligibility criteria defined by the Social Security Administration – not the same as Social Security Income.
T	Temperature
T.	Tablespoon
tsp.	Teaspoon
TID	Three Times a Day
TDD	Telecommunication Device for the Deaf
TPN	Total Prenatal Nutrition
TTY	Text Telephone
URI	Upper Respiratory Infection
UTI	Urinary Tract Infection
Via	Route to be given (G-tube, NG tube)
VLBW	Very Low Birth Weight
WIC	The special supplemental food program for Women, Infants, and Children. A program that provides food and nutrition education to prevent or correct malnutrition in pregnant women, new mothers and children up to age five. The program also screens for other health problems and makes referrals to other health and human services.

This publication was developed in part with funding from the Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB)/Division of Services for Children with Special Health Care Needs (DSCSHN) through Grant# H84MC07942

And in part with grants from Dignity Health for the Smooth Way Home Project with Feeding Matters, Southwest Human Development Easter Seals, and Raising Special Kids. For information on this NICU Parent Resource Manual, contact Raising Special Kids at 1-800-237-3007 or at info@raisingspecialkids.org

Conversion Table of Measurements - Commonly used for medication and drug computations

- 1 gram (g) = 1000 milligrams (mg)
- 1 kilogram (kg) = 1000 grams (g)
- 1 microgram (mcg) = .001 milligram (mg)
- 1 milligram = 1000 microgram (mcg)
- 1 liter (L) = 1000 milliliters (ml)
- 1 milliliter (ml) = 1 cubic centimeter (cc)
- 1 meter = 100 centimeters (cm)
- 1 meter = 1000 millimeters (mm)
- 1 cubic centimeter (cc) = 1 milliliter (ml)
- 1 teaspoon = 5 cubic centimeter (cc) = 5 milliliters (ml)
- 1 tablespoon = 15 cubic centimeter (cc) = 15 milliliters (ml)
- 1 tablespoon = 3 teaspoon
- 1 ounce = 30 cc = 30 ml = 2 tablespoons = 6 teaspoons
- 8 ounces = 240 cc = 240 ml = 1 cup
- 1 milliliter (ml) = 15 minims (M) = 15 drops (gtt)
- 5 milliliters (ml) = 1 fluidram = 1 teaspoon
- 15 milliliters (ml) = 4 fluidrams = 1 tablespoon
- 30 milliliters (ml) = 1 ounce (oz) = 2 tablespoons
- 500 milliliters (ml) = 1 pint (pt)
- 1000 milliliters (ml) = 1 quart (qt)

Weight

- 1 kilogram = 2.2 pound (lb)
- 1 gram (g) = 1000 milligrams = 15 grains (gr)

Length

- 2.5 centimeters = 1 inch

Centigrade/Fahrenheit Conversions

- $C = (F - 32) \times \frac{5}{9}$
- $F = (C \times \frac{9}{5}) + 32$



Having an infant in the neonatal intensive care unit can be frightening, bewildering, and exhausting. We understand that while you are focused on your baby's health, the other demands in your life have not vanished. Maybe we can help you now, or maybe you'd prefer to wait until further down the road.

Whenever you feel you'd like our help, Raising Special Kids is here for you.

We can help with many different kinds of questions related to your child's development, health and education services, insurance issues, and parenting. We can also put you in touch with another parent who has brought a child home from the NICU and understands the questions and concerns that you may have.

Our services are available at no cost and throughout Arizona in English and Spanish.

Please call or visit us online. We'd love to hear from you.

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800-237-3007

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