



Starter Kit for Children with Special Needs

As we face life's challenges as parents, we want to be sure we are able to meet all our children's needs. Your child may be severely injured, or diagnosed with an illness that effects their development. We hope this kit is comprehensive, no matter why you are reading it.

This kit can be used at any point during the journey you'll take with your child, traveling through the complicated and complex landscape of agencies and their terminology. In this kit are useful tips and resources to help you along the way.



Where to begin

You child has been diagnosed as having “special needs.”

What does this mean?

Children with special needs are those who have, or who are at increased risk, for a persistent physical, developmental, behavioral or emotional condition, and who require services of a type or amount beyond that required by children generally. (Merle McPherson, MD, *Pediatrics*, July 1998)

Why is your child different than other children?

Your child is no different than any other child, except that he or she needs the right tools to achieve a life of quality and satisfaction, and to be fully included in your community.

If you feel isolated, you are not alone.

Nine million American children under 18, about 13 percent, have a special health care need (Safe Kids Worldwide). Children with special needs are more like other children than unlike them. All children need to be cared for, loved and supported.

You may not know what to do next.

This packet can help you access the first resources and services you will need to get help for yourself and your child. You will find “Insider Tips,” as well as tools to use, gathered from those who have already learned how to navigate the “disability system.”

Don't forget, take one day at a time.

Don't let one day overpower you. Write down your thoughts and share them with others. Find a support group.



Finding your support systems

Families with children who have special needs are faced with a large complicated system that provides the services they need. Each agency and program has different rules and regulations. Often you will need to find your way, or “navigate,” after someone explains the process to you. They all require you, the parent, to successfully advocate for your child.

The laws that guarantee the rights of individuals with special needs do not always translate into comprehensive (complete or broad) services. Some programs offer services that overlap (provide the same thing) with those provided by another program. Some services are “fragmented,” so you may have to look very carefully at several different programs to find the one offering the comprehensive service you need.

As a result, the parent who is more skilled in advocating or promoting their child's needs is more likely to obtain the services. In other words, the parent who can ask for services, and not be shy or passive about it, may get more for his or her child.

Families need support to access healthcare, understand and obtain benefits; legal rights, and advice or representation; learn to navigate the system; and find referrals, protection and education.

Families also need peer-to-peer support. You will need this support throughout your child's life, but especially during transitions, like the one you'll experience when your child first goes to school.



Keeping Your Child Safe From Injury

We know that children with physical, psychological, cognitive, emotional or social special needs have much higher rates of injury. This may partly be due to a lack of prevention education.

We hope the enclosed information will help keep your child safe from injury.

Inside you'll find:

- Keeping your child safe from falls, choking and fire
- Keeping your child safe in cars if your child has:
 - Behavioral challenges, autism, ADHD or cognitive impairment
 - Cerebral palsy
 - Down syndrome
 - A spica cast
 - A special medical condition
- A summary of car seat options
- Car Safety: While in the car



Letters of Medical Necessity

Sample 1: This sample can help you get reimbursed from your insurance; modify it as needed.

Date:
Re: car safety restraint
DOB:
Insurance:

To Whom It May Concern:

_____ is a five-year-old with a diagnosis of global developmental delay and seizure disorder. This patient is unable to sit in a standard booster seat because of behavioral issues. He is over the weight limit for a child restraint with a harness, and will not stay in position in a regular booster seat. This presents a danger to him and the other occupants of the vehicle. He is therefore in need of an EZ-ON vest car safety restraint device to provide him with a harness at the shoulders and trunk. This restraint is also tethered to the back of the car for additional safety. It is equipped with a back closure so that the patient will not be able to remove it. The parents have tried this restraint on a loaner basis and have had success with this positioning. They have a tether anchor mounted in the car to support this restraint.

The child's need for safety has not previously been met and the child cannot be properly secured in the car without the prescribed car safety restraint. Both California law and best practice dictate that children under 6 or under 60 pounds be secured in an approved child restraint. The patient's behavior makes it unsafe for him to use a standard vehicle restraint. The EZ-ON vest in size adjustable, small, with a zipper closure, is medically necessary for this patient's care.

Sincerely,

_____ OTR/L
_____ MD



Letters of Medical Necessity

Sample 2: This sample can help you get reimbursed from your insurance; modify it as needed.

Date:
Re: car safety restraint
DOB:
Insurance:

To Whom it May Concern:

_____ is a 6-year-old with a diagnosis of fragile X syndrome. This patient is unable to sit in a standard booster seat because of behavioral issues. He is over the weight limit for a child restraint with a harness, but will not stay in position in a regular booster seat. This presents a danger to him and the other occupants of the vehicle. He is therefore in need of an EZ-ON Vest car safety restraint device and Ride^Ryte booster seat to provide him with a combination harness system and booster seat. The vest provides restraint at the shoulders and trunk and is tethered to the back of the car for additional safety. It is equipped with a back closure so that _____ will not be able to remove it. The booster provides improved positioning of the vehicle seat belt low on the pelvis, avoiding dangerous positioning on the abdomen. The parents have tried this restraint on a loaner basis and have had success with this positioning. They have had a tether anchor mounted in the car to support this restraint.

The child's need for safety has not previously been met and the child cannot be properly secured in the car without the prescribed car safety restraints. The patient's behavior makes it unsafe for him to use a standard vehicle seat belt system. Therefore, the EZ-ON Vest (Model 103Z) in size adjustable, XXS, with a back zipper closure, and the Ride^Ryte booster seat (full back) are medically necessary for this patient's care.

Sincerely,

_____ OTR/L
_____ MD



Letters of Medical Necessity

Sample 3: This sample can help you get reimbursed from your insurance; modify it as needed.

Date:
Re: car safety restraint
DOB:
Insurance:

To Whom it May Concern:

_____ is almost 10 and has a diagnosis of spastic quadriplegic cerebral palsy. The patient is unable to sit in a standard child safety restraint (booster seat) because of her decreased head and trunk control, and decreased postural support. _____ also demonstrates excessive extensor thrust, making it difficult to position her in a car seat. She has been traveling in a standard forward-facing child restraint despite being over the weight limit for harness use (40 pound limit — she is 45 pounds), or using a tumbleforms positioning seat, which is not a car seat and cannot be installed in the vehicle.

_____ is therefore in need of a Snug seat Traveller Plus car seat to provide her with additional support. This specialty restraint is made specifically for children who need harness restraint beyond the standard 40 pounds weight limit, providing a five-point harness for children up to 105 pounds. The restraint is also tethered to the back seat of the car for additional safety. Instruction was given to the parents on installation and positioning. The family has tried this restraint on a loaner basis and has had success with this positioning.

The child's need for safety has not previously been met and the child cannot be properly secured in the car without the prescribed car safety restraint. The patient's extremely poor head and trunk control make it unsafe for her to use a standard vehicle restraint or a standard booster seat. Therefore, the Snug Seat Traveller Plus car seat with a seat depth extender (for growth) is medically necessary for this patient's care.

Sincerely,

_____ OTR/L
_____ MD



Letters of Medical Necessity

Sample 4: This sample can help you get reimbursed from your insurance; modify it as needed.

Date:
Re: car safety restraint
DOB:
Insurance:

To Whom It May Concern:

_____ is a 5-year-old with a diagnosis of cerebral palsy and hydrocephalus, who presents with poor head and neck control due to hypotonic neck/trunk musculature. As a result of this decreased muscle control, this patient is unable to sit in a standard child safety restraint. Standard seats require upright positioning, which she cannot tolerate secondary to poor head control. She is currently traveling in a standard forward-facing child restraint with broken parts that is not providing her with the support she needs.

_____ is therefore in need of a Britax Boulevard car seat to provide her with additional support and adequate occupant protection. This restraint is for children who need a harness beyond the standard 40-pound weight limit, providing a five-point harness up to 65 pounds. As she now weighs 34 pounds, this will allow for future growth. Additional features which are beneficial for _____'s positioning needs include side impact protection wings, which will serve as lateral head supports, and a recline in the forward-facing position, which assists with her head and trunk positioning. This seat does not require special installation and will allow the child's mother to use friends' and family vehicles for transport, necessary in her case.

The child's need for safety has not been previously met and the child cannot be properly secured in the car without the prescribed car safety restraint. The patient's decreased head and neck control make it unsafe for her to use a standard child restraint, and she will continue to require a harnessed car seat long beyond the traditional 40-pound weight limit allowed by standard seats. Therefore, the Britax Boulevard car seat is medically necessary for this patient's care.

Sincerely,

_____ OTR/L
_____ MD





Keeping Your Child Safe From Injury

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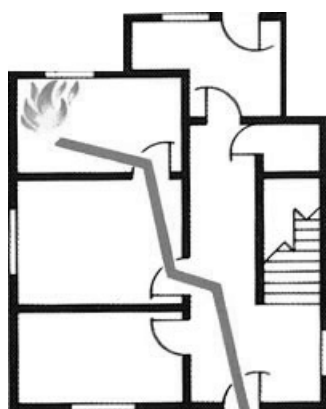
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Keeping Safe: From falls, choking and fire



Remember to change the batteries on your smoke detector when you adjust your clock every spring and fall.



Every family should plan and practice an escape route from their home in case of fire.

Keeping Safe From Falls

Caregivers often assume that children with limited mobility are not at risk for falling. Your child should never be left unsupervised because he could possibly roll or creep to danger. Even a fall from a bed or low elevated surface can cause injury. Your child should also be carefully watched at the playground. He should have developmentally appropriate play equipment, and a soft surface to walk, crawl or slide on. Children with seizure disorders may need to wear a helmet during play, and especially in the shower.

Keeping Safe From Choking

Children with special needs are more at risk for choking. Make sure you remove all strings on your child's clothes, and cover Band-Aids with clothing. Do not allow your child to play with latex balloons. They may bite it and choke on the pieces. Clean the floor carefully. Food that has been dropped or loose pieces from an older child's game may become choking hazards if your child puts them in his mouth. Cut food into small pieces, and make sure your child is sitting upright and supported when eating, or being fed.

Keeping Safe From Fire

Install smoke detectors outside each bedroom. Change the batteries when you adjust your clock every spring and fall. If possible, children should be taught how to stop, drop and roll. If your child cannot crawl or walk, keep a blanket or scooter board nearby. In case of fire, secure your child to the board or inside the blanket, and drag your child to safety. If a child doesn't speak, it may help to keep a bell or whistle in the room so he can alert you in case of danger. Every family should plan and practice an escape route from their home in case of fire. Practice using a buddy system if your special needs child has brothers or sisters. All children should be taught what a fireman wears (equipment and mask) so they do not become frightened and hide in an emergency. The fire department closest to your home should be contacted to let them know there is a child with special needs at that address. They should be advised if there is an oxygen tank in the home, any special equipment in use, such as a ventilator, and if the child is mobile.

Car Safety: If your child has behavioral challenges, autism, ADHD (Attention Deficit Hyperactivity Disorder) or cognitive impairment

Children showing signs of behaviors such as impulsiveness, distractibility or a short attention span may be unable to stay secured in a car seat, and could become a serious distraction to the driver. Families may have to try a variety of seats to see which one is the most secure restraint.

Harness systems may be helpful, but must be properly secured and snug. Child safety seats with harness systems for use by children weighing more than 40 pounds may also be useful.

Another option is the E-Z-ON Zipper Vest. This travel vest is perfect for a child who needs extra restraint. The vest eliminates the worry of unbuckling that you have with a standard car seat. The vest you want is model #101 and fits age 2 to adult, from 20 to 168 pounds.

E-Z-ON Products makes harnesses and vests for vehicles with lap-only rear seat belts and for children with special needs, including the 86-Y and Kid-Y harness.

E-Z-ON will refer you to a distributor in your area. Visit their Web site at www.ezonpro.com.

Another travel vest is the RideSafer vest. It is available to consumers at www.allegromedical.com.

Some older children with behavioral challenges may be transported in a conventional booster seat, or by combining a booster seat and a vest. One option may be the Ride^Ryte booster seat, used in combination with the E-Z-ON Kid-Y harness (the Kid-Y harness cannot be used alone). Details about this booster seat and the harness are available at www.safetyangel.com and at www.ezonpro.com. You will be referred to a distributor in your area. Boosters lift your child up, may be more comfortable, give a better view out the car window, and improve your child's attitude about being restrained.



E-Z-ON zipper vest (front and back)



Ride^Ryte booster seat



E-Z-ON Kid-Y harness

Car Safety: If your child has cerebral palsy

Since many children with CP have poor head, neck and trunk control, they benefit from riding rear-facing as long as possible. In a crash, when children are riding facing the back of the car, crash forces are spread over the back of the safety seat and the child's back, reducing their risk of neck and spinal cord injuries.

Avoid using a makeshift restraint system. Your child may be able to use a standard car seat restraint once he outgrows a rear-facing seat and has to ride forward-facing. He may be better positioned if he rides in a convertible, such as the Evenflo Triumph V, or in a forward-facing only seat, like the Nania Airway, that can be semi-reclined.

Sitting in a semi-reclined position can help keep your child's head from falling forward. Rolled blankets or foam placed along each side of your child can help keep his head and torso centered. The Britax Regent (formerly called the Husky) has a very wide base, and is sometimes an option for the larger child. This seat fits a child weighing 22 to 80 pounds and up to 53 inches tall.

Children with poor upper body strength will require the support of a vest or a large medical seat, once they outgrow a standard child safety seat. There are several vests suitable for family vehicles pictured and described in detail at www.ezonpro.com. E-Z-ON will refer you to a distributor in your area. Another travel vest possibility is the RideSafer vest. It is available at Prevention Alternatives: Call 517-927-7731.

It is a good idea to work with a rehabilitation therapist when selecting and ordering an adaptive restraint that best meets your child's positioning needs. Since a large medical seat is much more expensive than a standard seat, the therapist can also help you get funding from a "third-party payer" such as medical insurance, California Children's Services, or a charitable or service organization like United Cerebral Palsy or Kiwanis.



Evenflo Triumph V



Safe Traffic Systems RideSafer vest



Britax Regent

Please see sample "Letters of Medical Necessity" section of this kit.

Car Safety: If your child has Down Syndrome

A child with Down syndrome may have low muscle tone. In some children, the first and second vertebrae in their neck move easily. A rear-facing car seat will better protect your child's head, neck and spine.

Many children with Down syndrome need heart surgery. If you are concerned about car seat harness straps placing too much pressure on their sutures, you may want to consider a different car seat. Try to continue having your child ride in the rear-facing position; strap pressure in a crash is less for rear-facing children than for children riding in the forward-facing position.

There also may be a car bed that will fit your child, like the Snug Seat car bed. It fits babies up to 21 pounds and 29-1/2 inches in length. This bed comes with a "sleeping bag" bunting that better protects the chest and abdominal area. Although it is no longer manufactured, some may still be available through hospital loaner programs.

A child with low muscle tone will need extra support to sit properly in a car seat. Place rolled receiving blankets or towels along your child's sides to help hold him in position. Never put anything under or behind your child.

If your child has loose ligaments, it may be easier for him to wiggle out of his car seat. Consider other options to keep him restrained. Travel vests work well for children with neuromuscular weakness, cerebral palsy (CP) or Down syndrome. Several types suitable for family vehicles are pictured and described in detail at www.ezonpro.com. E-Z-ON will refer you to a distributor in your area. Another travel vest option is the RideSafer vest. It is available at Prevention Alternatives: Call 517-927-7731.

If your child has poor neck control, special needs car seats that come with wedges, bars, positional padding and seat depth extenders may work better. For some toddlers, a convertible, such as the Combi Victoria or a forward-facing-only seat, like the Nania Airway, that can be semi-reclined, may work well.

You can add crotch rolls between the child's legs to prevent slumping. Foam rolls can provide side support. Soft padding that doesn't alter harness function can be positioned on either side of the head.

Never place padding behind or under the child in the seat and never secure your child's head separately to a car restraint to keep it from falling forward. If your child has a tracheostomy, do not use a child restraint with a tray or shield. A forward fall could cause an injury to their airway.



Evenflo Titan V



Combi Victoria



Do not use a car seat with a shield if your child has a tracheostomy.

Car Safety: If your child has a spica cast

Hippo

Your child may require a spica cast to correct developmental dysplasia of the hip, hip instability due to Down syndrome, or a femur or pelvic fracture from a traumatic injury.

The Spelcast spica car seat manufactured by Snug Seat was replaced in March 2006 with the Hippo spica car seat designed by Snug Seat and Britax.

The Hippo is a car seat that may be used rear-facing, semi-reclined, for a child who is between 5 and 33* pounds or forward-facing for a child who is over one year of age and between 20 and 65* pounds and a maximum of 49 inches in height. The Hippo must be installed forward-facing in the upright position if the child's weight is between 34 and 65* pounds, but may be installed forward-facing in the semi-reclined position for children less than 33* pounds. This seat must be tethered if the child is 40 pounds or more. The Hippo is available at www.snugseat.com, and www.adaptivemall.com. (*Upper weight limit refers to casted weight)



Snug Seat Hippo



E-Z-ON modified vest



Nania Airway

E-Z-ON vest

Another option for children in spica casts is called the modified E-Z-ON vest. This vest is for children aged 2 to 12 and weighing from 20 to 100 pounds. The 101M2 better fits children who are 5 to 12 years old, 65 to 100 pounds. The M203-XS fits snugger on children 2 to 5 years of age, 20 to 65 pounds. When using the modified E-Z-ON vest, your child must travel lying down in the rear seat of the vehicle. See www.ezonpro.com for referral to a distributor in your area.

Hospitals or other institutions may purchase the Hippo and the modified E-Z-ON vest from Prevention Alternatives: Call 517-927-7731.

If your child's surgery is scheduled in advance, you'll have time to arrange transportation ahead of time. Call your orthopedic surgeon or the surgeon's staff to set up safe transport home.

The surgeon is usually able to tell you the approximate size of the cast, that is, how wide it will be, and how much it will bend at the knees. Children in spica casts often fit in a conventional car seat.

One option, for example, may be the Nania Airway; it can semi-recline and has low sides. Unfortunately, this car seat was discontinued in 2006 but may be available through hospital loaner programs. Any convertible seat with lower sides and a wider front may work. The hospital should have a variety of seats to try. You may want to look at the Britax Regent (formerly called the Husky), Roundabout, Marathon and Boulevard (formerly called the Wizard), the Dorel Alpha-Omega, the Combi Victoria or the Combi Avatar. Sometimes a small baby may fit into a car bed, depending on how their cast is made.

Car Safety: If your child has a “special medical condition”

Such as osteogenesis imperfecta, myelomeningocele, gastroschisis, or Pierre Robin sequence.

Special child passenger restraints called car beds are available for infants who must travel lying down on their stomach, back or side. These restraints are used for special medical conditions as well as for premature infants who are not able to ride at a 45 degree angle and maintain normal breathing.

The AngelRide holds infants from 4 to 9 pounds and up to 20 inches in length that must ride flat. It has a wraparound three-point harness. You may buy the AngelRide direct at www.angel-guard.com/buy.html or from www.adaptivemall.com.

The Cosco Dream Ride SE fits infants from 5 to 20 pounds, and 19 to 26 inches in length that must lie flat. It has a three-point harness. You may buy the Ultra Dream Ride direct from www.allegromedical.com.

Both may be purchased by hospitals, organizations and institutions from www.mercurydistributing.com, a wholesale distributor, or from Prevention Alternatives: Call 517-927-7731.

The Snug Seat car bed is a larger, deeper bed that accommodates infants from 5 to 21 pounds, and up to 29-1/2 inches in length. This bed is for infants with conditions requiring them to lie flat or on their sides. A special bunting is provided based on your infant’s measurements. The infant is zipped up in the bunting and secured to the bed with Velcro straps.

Snug Seat no longer manufactures this bed, but it may be available through hospital loaner programs.

Your baby may be premature, has passed the Angle Tolerance Test in the NICU, is able to ride in a car seat, instead of a car bed, but is still under 5 pounds at discharge. He or she may be able to fit a Graco Assura, the Chicco Keyfit or the Compass 1-420.



Angel Guard AngelRide



Cosco Dream Ride SE



Snug Seat

Insider TIP:

Never use a car bed without a prescription from a medical services provider.

Car Safety: Summary of medical car seat options



Britax Traveller



Columbia



Carrie



Special Tomato

Consumers may find some special safety products difficult to find through stores. Purchases may be made directly from Prevention Alternatives' Web site: www.stores.ebay.com/safety-products-for-families.com.



Roosevelt

There are also several medical seats that may be suitable for your child. These seats accommodate larger children and children with special medical conditions.

- The Britax Traveller Plus fits children weighing from 22 to 105 pounds who are 30 to 56 inches tall.
- The Columbia fits children from 20 to 102 pounds who are up to 60 inches tall.
- The Special Tomato comes in size small for children 2 to 8, and in size large for children 8 to 14.
- The Carrie seat is available in four sizes, ranging from its preschool size, for children weighing up to 20 pounds, on up to a small adult size for those weighing up to 130 pounds.

Several companies sell these child passenger restraints directly to consumers, including:

- www.adaptivemall.com
- www.allegromedical.com

Other possibilities include the Recaro Start Plus booster seat, with a turning frame, that fits a child from 30 to 80 pounds and up to 59 inches in height or the Peppino, which has stroller options and fits a child up to 55 pounds and from 37 to 46 inches in height.

A new seat has become available called the Roosevelt. It fits a child 35-115 pounds and from 33.5 to 62 inches in height. This car seat from Merritt manufacturing company features an installation mode that does not require a tether. The Roosevelt may be purchased from: www.eztether.com

Some medical car seats are available to hospitals, organizations and institutions at Prevention Alternatives: 517-927-7731. Others are available at www.adaptivemall.com. The Recaro is available to consumers at www.allegromedical.com.

Work with a specialist in rehabilitation, such as an occupational therapist, to determine which restraint is best for your child. Try different types of restraints to see what works best for you and your child.

Keep in mind the type of car you own, its age, how many children will be seated, as well as your child's special needs. Put together a care plan for your child's special medical condition. The plan should also outline what to do in a transportation emergency.

Transportation issues should be included in the Individual Family Service Plan (IFSP) you write with regional center staff and the Individual Education Plan (IEP) you write with your child's school.

You may need technical assistance. Large seats require one to two tethers and heavy-duty hardware. Help is available.

Ask your child's therapist to call the Riley Hospital for Children in Indianapolis for expert advice on all transportation needs. One of their programs is the National Center for the Safe Transportation of Children with Special Healthcare Needs. Call 800-755-0912, or visit www.preventinjury.org/NationalCenter.asp.

Special needs car seats are very expensive. You or your child's therapist must write a "Letter of Medical Necessity" (see letter samples in this kit) to try to get reimbursement from your medical insurance provider.

Car Safety: While in the car



If you are carrying medical equipment, such as an oxygen tank, monitor or portable suction device, secure these items to the vehicle floor or under the seat, so they will not become projectiles in a motor vehicle crash. In a collision, small objects become dangerous missiles making impacts of 20 to 30 times their weight.

Using Electrical Equipment

Electrical equipment used during transport should have portable self-contained power for twice the expected time of the trip.

Checking Your Child Restraint For Proper Installation

For information on getting a car-seat check-up in your area call 800-441-1888 or visit www.usa.safekids.org.

Make sure your car seat is installed correctly and is the best car seat to fit your child's needs.

If your child cannot be properly restrained, we recommend using an ambulance instead.

A list of child passenger safety technicians who have been certified in special needs transportation at the Riley Hospital's Automotive Safety Program is available at www.preventinjury.org/SNTtrainedPpl.asp.



Learning more about Special Needs Transportation Issues

To learn more about special needs transportation, visit the Riley Children's Hospital's Children Automotive Safety Program at www.preventinjury.org or the American Academy of Pediatrics at www.aap.org.





Helpful Tips



Helpful tip: **Institutional deeming**

Medicaid Waiver Institutional Deeming is a process you can use to get full scope Medi-Cal coverage that's unrestricted, without a share-of-cost, for a special needs child from birth to age 18. Full scope Medi-Cal coverage gives you access to all Medi-Cal services, including medical, dental and EPSDT* (Early and Periodic Screening Diagnosis and Treatment) supplemental services.

Deeming enables your child to apply for Medi-Cal regardless of the parent's income. The child must first meet all Medicaid Waiver Program requirements.

Eligibility Requirements for Deeming

Child must:

- Be a permanent (not Early Start) regional center client
- Have a Social Security number and be legally documented
- Be under 18 and living at home with parents
- Not already be eligible for Medi-Cal based on parent's income
- Have two or more qualifying conditions on the CDER** (Client Development Evaluation Report) under self help, motor, social/emotional domains, special healthcare conditions or extensive medical needs
- Already receiving funding from their regional center for a service that is approved by the Medicaid Waiver Program (many services are eligible, including infant development programs, respite and more).

After eligibility for institutional deeming is established, a referral is sent to the county Medi-Cal office. An eligibility worker will set up an appointment with your family. Your child is then issued a Medi-Cal number.

** EPSDT Services include: In-home nursing; occupational therapy (OT); physical therapy (PT); speech; communication devices; medical equipment; nutrition; counseling/mental health; therapeutic behavioral services.*

*** CDER: Client Development Evaluation Report, Department of Developmental Services (DDS). The CDER qualifying condition is determined by the case manager, Medicaid Waiver nurse, and the physician team at the regional center.*

Insider TIP:

If your child has Medi-Cal share-of-cost, this can be waived through institutional deeming.

If your child has private insurance, he/she can apply for institutional deeming. The first payer will be the private insurance; Medi-Cal is then billed for services that aren't covered.



Helpful tip: Preparing for emergencies and disasters

Preparing for an emergency or disaster can be an overwhelming and difficult task. Preparing in advance can help you be ready. We recommend stockpiling a two-week supply of food and water, as well as first-aid supplies, clothing and bedding, tools and other emergency supplies. Think of what other necessities are essential for your family. Do you have an adequate supply of medication and a safe place to store it? How will you keep medical supplies sanitary and maintain electrical backup for your medical equipment?

A disaster plan should include information like:

- Where to go should a disaster occur
- The best evacuation route out of your neighborhood and to local shelters
- The name and phone number of an out-of-state contact person
- What to do with family pets.

Find out if your child's school and your workplace have disaster plans. Make sure important information about your child's special needs is included in the school's plan. Medical information forms are available online at <http://64.92.175.22/fileupload/File/Personal-Disaster-Preparedness-Guide-PDPG.pdf>. The form can be customized to include every family member.

What do emergency response staffers or other people need to know about your child's special needs? Note any special communication needs, medications and how to make your child comfortable if ambulatory devices need to be left behind. Consider purchasing a Medic Alert bracelet (www.medicalert.org) or a similar product so that medical information is kept close to your child's body at all times.

You will find an identification card in this kit that can be placed inside a luggage tag and attached to a wheelchair. Place an ID tag on your child's car seat that includes medical information. Be sure to safely store medical information forms and copies of other important personal and financial documents in your disaster preparedness kit.

Finding out what emergency preparedness programs are available in your community is easy. For example, Berkeley and Oakland have implemented a program called 9-1-1 Computer Aided Dispatch. It can identify locations where people with special needs are living. Registering for the program is voluntary and the information collected also helps first responders if a 911 emergency call brings them to your home. Berkeley residents may call the Public Safety Communications Center at 510-981-5900 or visit www.ci.berkeley.ca.us/police/onlineforms.html to register.

Oakland residents may call the Oakland Fire Department, Communications Division at 510-238-3796 to have an application sent to them.

Insider TIP:

The American Red Cross is a good source for information. Visit their Web site at www.redcross.org.

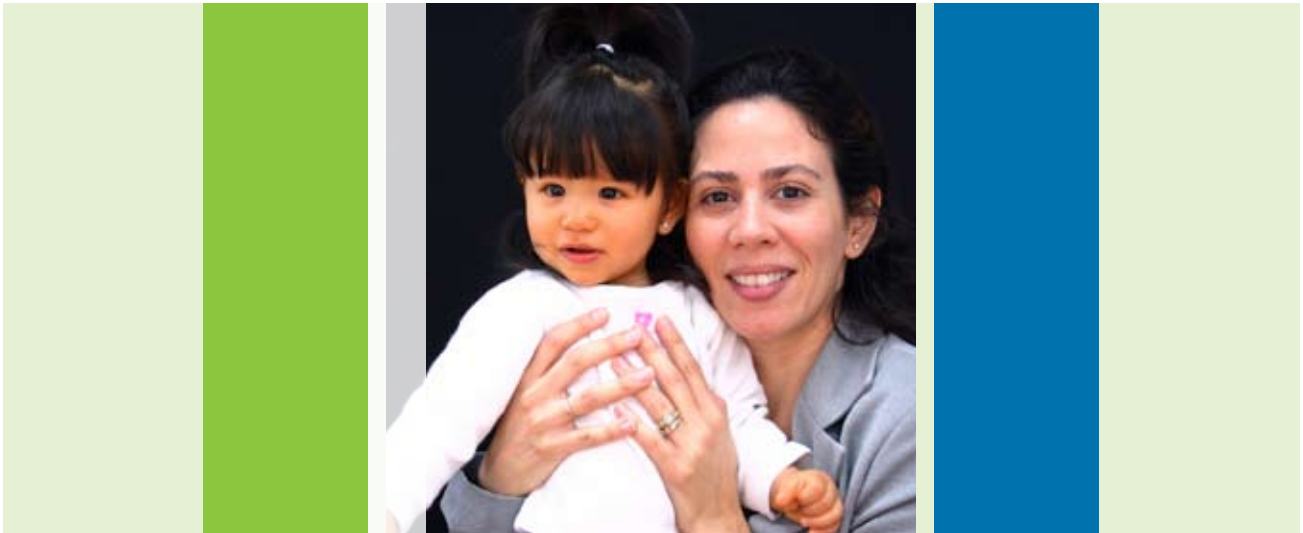
Other Web sites give tips on what to consider when creating a disaster plan and emergency preparedness kit for your family. There's more here:

- Prepare Now at www.preparenow.org
- Family Readiness Kit at www.aap.org/family/frk/aapfrkfull.pdf

Source: *The Family Resource Network (modified)*



Resources



Resources

Public Health Clearinghouse:

www.acphd.org

You can reach this toll-free information and referral line for health-related resources in Alameda County at 888-604-INFO (4636)

American Academy of Pediatrics Medical Home:

www.medicalhomeinfo.org

Family Voices:

www.familyvoices.org

Beach Center on Disability:

www.beachcenter.org

Disability Connections:

www.disabilityconnections.org.au/about.shtml

Family Village:

www.familyvillage.wisc.edu

Children's Regional Integrated Service System

www.criss-ca.org/

University Center For Excellence in Developmental Disabilities

<http://uscucedd.org/>



Resources

Contra Costa County Emergency Numbers

Office of the Sheriff Contra Costa County
www.cocosheriff.org

City of Concord
925-671-3220
www.cityofconcord.org/citygov/dept/pd.html

City of Walnut Creek
925-935-6400
www.walnutcreek.pd.com

Walnut Creek Police Department
925-943-5844

City of Richmond
510-233-1214
www.ci.richmond.ca.us./index.asp

City of Brentwood
925-634-6911
www.ci.brentwood.ca.us

City of Antioch
925-778-3911
www.ci.antioch.ca.us

City of Martinez
925-372-3400
www.cityofmartinez.org



Resource: California Children's Services (CCS)

CCS is a state program that pays for specialty healthcare services for eligible children with chronic medical conditions. CCS may cover medical conditions such as birth defects; blood disorders; cancer and some other tumors; cerebral palsy; endocrine and metabolic disorders; genetic conditions; heart disease and HIV/AIDS.

Your child is eligible if he/she is:

- Under 21 years of age
- Has a medical condition covered by CCS
- Is a resident of California
- Living with a family whose income is less than \$40,000, or if the family's income is \$40,000 or more and out-of-pocket expenses for the qualifying child are more than 20 percent of the family's income
- Has Healthy Families or Medi-Cal coverage.

Services

- Diagnostic evaluations to determine whether a condition is medically eligible. CCS also covers HIV testing.
- Treatment services include hospitalizations, surgeries, social services, nutritional consultations, equipment, supplies, medications and orthodontics.
- Therapy services include physical and occupational therapy at Medical Therapy Units (MTUs).

Referrals

A child may be referred by anyone, including yourself, a family member, the school staff, or a healthcare provider. Fill out a CCS referral form or write a letter that includes:

- Patient's name, address and phone number
- Date of birth
- Medi-Cal number (if applicable)
- Parent/legal guardian's name, address and phone number
- Medical condition
- Name, address, and phone number of referral source.

After a referral is made, a CCS application will be sent to you. Return the completed application with a medical report from your child's medical provider. Then the eligibility process begins.

Contact information

California Children's Services
Alameda County Public Health Department
1000 Broadway, Suite 500
Oakland, CA 94607
Phone: 510-208-5970
www.dhs.ca.gov/pcfh/cms/ccs

California Children's Services
Contra Costa County
597 Center Ave., Suite 110
Martinez, CA 94553
Phone: 925-313-6100
www.cchealth.org/services/ca_childrens_services/

Insider TIP:

Family income is not a barrier if your child is applying only for therapy services, needs diagnostic services to confirm a CCS-eligible medical condition, or was adopted with a known CCS-eligible medical condition.



Resource: Family Resource Centers

Family Resource Centers provide parent-to-parent support, information, and referral for families of children from birth to age 22, who have disabilities or special healthcare needs. All staff members are parents of children with special needs.

Eligibility requirements

Services are available to any parent of a child with disabilities or special healthcare needs. There are no income requirements; all services are free of charge.

Alameda County: Family Resource Network (FRN)

Services

- Offers peer counseling
- Produces a quarterly newsletter listing parent and professional training sessions
- Leads support groups that are disability-specific as well as linguistically appropriate
- Organizes social and recreational activities for teens
- Distributes a county-wide resource directory that is free to parents
- Presents trainings and support groups on a variety of topics related to parenting a child with special needs
- Assists parents with accessing educational, developmental, social and medical services
- Maintains a lending library, video collection and other educational materials

Contact information

5232 Claremont Avenue
Oakland, CA 94618
Phone: 510-547-7322
Email: Info@frnoakland.org

Contra Costa County: CARE Parent Network Services

- Offers peer counseling
- Produces a quarterly newsletter listing parent and professional training sessions and resources
- Leads support groups that are disability-specific as well as linguistically appropriate
- Distributes a county-wide resource directory that is free to parents
- Presents trainings on a variety of topics related to parenting a child with special needs
- Assists parents with accessing educational, developmental, social and medical services
- Maintains a lending library and other educational materials

Contact information

1340 Arnold Dr., Suite 119
Martinez, CA 94553
Web site: www.careparentnetwork.org
Phone: 800-281-3023 or 925-313-0999
Fax: (925) 370-8651
Email: careofarc@aol.com

Insider TIP:

The FRN and CARE offer workshops to help parents organize all their child's records. Parents are asked to bring all their records to a meeting, are given a 3-ring binder and are shown how to organize everything in different categories inside the binder. These workshops help busy parents get organized. The binders help them stay organized whenever they work with a new specialist or service provider. Workshop participants with organized binders don't have to search for papers or re-explain their child's history over and over again.



Resource: Regional Center of the East Bay (RCEB)

The center is a private, non-profit organization overseen by California's Department of Developmental Services. It provides entitlement services for people with developmental disabilities. Regional centers were established to comply with federal legislation, the Individuals with Disabilities Education Act (IDEA), and California's Lanterman Act.

California has 21 regional centers. Regional centers serve people of all ages and have no income restrictions. They are the "funders of last resort" so they will not pay for services that can be funded by a different source, like a school district or private insurance.

Early Start: Pathway 1, called "Status 1" Clients

The Early Start program provides family-centered early intervention services to eligible infants and toddlers (birth to age 3) who have or are at risk for a developmental disability.

Where and how early intervention services are delivered is determined by the family and the team members during the Interagency Family Service Plan (IFSP) conference. Services are provided in the "least restrictive," most "natural" environment, whether that is the home, or an agency program ("center-based") with other children.

Eligibility

An infant or toddler, from birth to age 3, is eligible when the child:

- Has a delay in at least one area of development
- Has a condition with a known probability of causing a disability
- Is at high risk of having a developmental disability due to a number of factors.

Referral

Anyone may refer a child for assessment—a parent, hospital, health care provider, public health department, social services staffer or childcare provider.

Referrals can be made through the second pathway, Status 2, at any time in a person's life, but the earlier services and support are received, the better.

Referrals made through the first pathway, for Status 1 eligibility, are often made by a clinician in a hospital intensive care nursery when a baby is discharged home with risk factors for developmental delay.

Services provided may include:

- Service coordination, also called case management
- Therapy services such as speech, physical and/or occupational therapy
- Vision and hearing services, including exams and programs
- Infant development programs delivered at home or at a center
- Medical services, including some specialties
- Parental support, counseling, respite (break or "breathing space" for caretaker) and training
- Nursing respite services, such as an RN, LVN, or CNA provided in the home, depending on the level of care needed
- Nutrition/feeding services
- Assistive technology, including assistive devices or services
- Psychological and social work services
- Transportation and related costs needed to ensure a child receives above services (such as transportation to and from a doctor's office or to therapy sessions).

Pathway 2, called "Status 2" Clients

Known developmental disability

Eligibility

Individuals with disabilities according to the following criteria:

- Child has a disability that begins before age 18, continues, or can be expected to continue, indefinitely, and represents a significant disability for that individual. This includes conditions such as mental retardation, cerebral palsy, epilepsy and autism. It also includes disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, but does not include other handicapping conditions that are only physical in nature.



- Individuals applying for regional center services go through an interdisciplinary process to determine their eligibility. If they are Early Start Clients (at risk for disability: “Status 1”), they will be eligible until their third birthday unless it has been determined by that time that they qualify to become a permanent RCEB Client (have a permanent developmental disability).
- If the individual qualified for eligibility through the 2nd pathway (an established disability: “Status 2”), then they automatically become a RCEB Client for life.

Contact information

Regional Center of the East Bay (RCEB)
7677 Oakport Street, Suite 300
Oakland, CA 94621
www.rceb.org

Early Start Program
Pathway 1, Status 1; child is at risk for developmental disability
510-383-1355

Other referrals
Pathway 2, Status 2; child has known developmental disability
510-383-1200



Resource: Medi-Cal

Medi-Cal is the name of California's Medicaid program. It provides health insurance for low-income families and those who would otherwise have no health insurance.

Medi-Cal is made up of several programs. The most common ones are:

- Fee-For-Service Medi-Cal
- Medi-Cal Managed Care (Alameda Alliance for Health, Blue Cross, Kaiser Cares For Kids, Healthy Families [outpatient services only])
- Share-of-Cost Medi-Cal
- Medi-Cal Waiver services
- Emergency Medi-Cal

Services

- Hospital inpatient care
- Equipment and supplies
- Laboratory tests
- Medical transportation
- Outpatient care
- Therapy
- X-rays
- Skilled nursing care
- Doctor visits
- Medications (medicines the healthcare provider orders)

Eligibility Requirements

- Public assistance recipients
- CalWorks recipients
- SSI (Supplemental Security Income) recipients
- Some low-income families and individuals who are low-income but do not otherwise qualify
- Medically Needy/Medically Indigent

Fee-For-Service Medi-Cal

Recipients receive health care from any Medi-Cal provider without going through a health plan. For example, people who are on SSI or children who are in foster care qualify for this program.

Medi-Cal Managed Care

These are state-approved health insurance plans that are paid to provide care to Medi-Cal recipients. The individual chooses one of the approved county plans and then receives their healthcare through any provider registered with that plan.

Share-of-Cost Medi-Cal

This Medi-Cal plan offers healthcare insurance to families and individuals whose incomes are too high for regular Medi-Cal but too low to cover their health care costs. The "share of cost" is the amount of money that Social Services determines the recipient must pay their healthcare providers each month before Medi-Cal will help.

Medi-Cal Waiver Services

A federal waiver allows the state to provide Medi-Cal to some people who might not otherwise be eligible. It allows home and community services to be provided instead of hospitalization. For example, a child with special healthcare needs might obtain Medi-Cal in order to receive services so he/she could live at home instead of in an institution.

Emergency Medi-Cal

People who would otherwise be ineligible for Medi-Cal, for example, due to their immigration status, may apply for Medi-Cal Emergency services.

- Medically Needy (MN) Uninsured families, those whose incomes are too high to qualify for cash assistance, but who otherwise qualify for CalWorks or SSI/SSP
- Medically Indigent (MI) low income pregnant women, children under age 21, and some adults in long term care who do not qualify for public assistance or as medically needy

Federal Poverty Level (FPL) Programs

- Pregnant women and infants in families with incomes at or below 200 percent of FPL
- Children aged 1 to 5 in families with incomes at or below 133 percent of FPL
- Children aged 6 to 19 in families with incomes at or below 100 percent of FPL

Referrals

You may go to the county social services office or meet with an eligibility worker at a community-based program, or in a hospital where medical care is needed. An eligibility worker will help you fill out the forms, and will collect information and documentation. You will need proof of your income and address. You will be notified by mail within 45 days if you have been enrolled. There are two exceptions: (a) SSI/SSP recipients are automatically eligible; and (b) children and pregnant women may enroll with a mail-in application. Call 888-999-4772 to get an application.

Contact information

Medi-Cal phone number: 510-639-1000

Medi-Cal toll free: 800-541-5555

Get Medi-Cal application by phone: 510-777-2300

Web site: www.medi-cal.ca.gov



Resource: Mental Health Services

There are many reasons your child may need mental health services.

Family history may put some children at risk for mental health disorders. Others are at risk because of community or family problems, including street violence, domestic violence, an alcoholic parent, poverty, bullying at school, loss of a loved one or other reasons. In a very young child, the symptoms of a mental health disorder may appear as difficulty regulating behavior or forming attachments to other people.

Treatment services usually focus on children with a mental health disorder that affects their ability to function in childcare, school, at home or in the community.

Your child may be diagnosed with a mental health disorder if he or she:

- Has major difficulty making and keeping personal relationships
- Displays inappropriate behaviors and feelings
- Is persistently unhappy
- Has physical symptoms that prevent participation in daily activities.

Alameda County Behavioral Health Care Services (BHCS)

Alameda County Behavioral Health Care Services coordinates mental health treatment in Alameda County. BHCS offers access to treatment and support programs which help children with mental health needs, including those with Serious Emotional Disorder (SED). To get help, call the ACCESS 24-Hour Hotline at 800-491-9099.

Contra Costa County Mental Health Services (CCCMHS)

Regional mental health clinics provide counseling for children and families. Staff can provide information about mental health resources including the county's specialized services for people who are seriously emotionally disturbed.

For psychiatric emergencies go to Contra Costa Regional Medical Center (north side), 2500 Alhambra Ave., Martinez. 800-678-7277.

West County residents: 256 24th St., Richmond, M-F, 8 a.m.-5 p.m.

www.cchealth.org/groups/mental_health/youth_families.php.

Eligibility Requirements

- Young children and youth in the community with mental health disorders who are either on Medi-Cal or are medically indigent
- Children receiving special education services who have been referred by their school to receive mental health services under AB 3632 ("AB" means Assembly Bill, a state law)
- Children in psychiatric inpatient facilities
- Dependents of the juvenile court with mental health needs

Agencies

Services are provided by county and community-based organizations that contract with the county to provide these services. BHCS also operates four children's outpatient mental health programs:

- San Leandro - Eden Children's Services
- Oakland - Oakland Children's Services
- Fremont - Tri-City Children and Youth Services
- Pleasanton - Valley Community Support - Children's Services

Referrals

Call ACCESS, a 24-hour member helpline that answers questions about finding and receiving behavioral health services. The ACCESS line also reviews Medi-Cal eligibility for mental health services.

Contact information

800-491-9099 ACCESS/Alameda County Behavioral Health Care Services 24-Hour Hotline

Family Stress Center/ Contra Costa County

Individual, couple, child and family therapy.
Concord: 925-827-0212
Antioch: 925-706-8477



Resource: Other Mental Health Services

Medi-Cal's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)

This program is an "entitlement" (your child has the right to these services) for children from birth to age 21 years who are Medi-Cal eligible. The program provides complete mental health services to correct or improve mental health problems. Case management and coordination are also provided. Family members, and other providers of your child's services, are included in the treatment plan.

More money is available for mental health services in Alameda County for children from birth to age 5 years, children in foster care, children with a dual diagnosis of substance abuse and mental illness, and for school-based services.

Call ACCESS at 800-491-9099 to get a list of participating programs. You can also find an interagency referral guide at www.ackids.org under "What's New."

Referral

EPSDT mental health services referrals can be made through ACCESS or by calling the agency directly.

Contact information

Call the ACCESS/Alameda County Behavioral Health Care Services 24-Hour Hotline at 800-491-9099

Web Resource

www.ackids.org/whatsnew.htm
Early Childhood Mental Health and Parenting Services and Inter-Agency Referral Guide-EPSDT Programs for children 0 to 5.

Contra Costa Health Access Coalition

The coalition is an inclusive, broad-based partnership of organizations and individuals whose mission is to improve access to care for all children and families in Contra Costa County. Call 925-313-6254.
Email: lmartine@hsd.cccounty.us

Insider TIP:

If the mental health need is related to a CCS-eligible condition, then the mental health services should be provided through CCS.

Healthy Families Program

Healthy Families provides two mental health benefits:

- Basic mental health services for children who do not have a Serious Emotional Disorder (SED) diagnosis
- Drug/Alcohol treatment services

Referrals

- Your child's primary care provider, such as a pediatrician or nurse practitioner
- ACCESS/Alameda County Behavioral Health Care Services 24-Hour Hotline: 800-491-9099
- Healthy Families Program: 888-747-1222
- California Children Services (CCS): 510-208-5970

Special Education Program - AB 3632

("AB" means Assembly Bill, a state law)

This program combines educational and other mental health services to students in an "interagency model," through their school district. Students receiving special education services who have been determined to be in need of mental health treatment in order to benefit from their education are eligible.

Referrals

Services can be started by your child's local school district.

- Call your child's local school district's Department of Education.

Below are phone numbers for the Special Education Local Planning Area (SELPA) offices:

- Alameda/Albany/Berkeley/Emeryville/Piedmont: 510-337-2352
- Oakland: 510-879-8223
- Castro Valley/Hayward/San Leandro/San Lorenzo: 510-537-3000
- New Haven/Newark/Fremont: 510-659-2569
- Dublin/Livermore/Sunol Glen/Mountain House Elementary/Pleasanton: 925-426-9144

Contact information

Call the ACCESS/Alameda County Behavioral Health Care Services 24-Hour Hotline at 800-491-9099.



Resource: Oral/Dental Health Services

Each of the programs below provides oral health services such as preventive care and treatment of dental conditions. There are also a few community-based programs offered through dental schools and non-profit organizations.

- Office of Oral Health
- Child Health and Disability Prevention Program (CHDP)
- Medi-Cal's Denti-Cal program
- California Children's Services (CCS)
- Healthy Families
- Regional Centers

Child Health and Disability Prevention (CHDP)/Denti-Cal

Children with special needs who have Medi-Cal or are CHDP eligible, may receive dental services, including preventive care, through a provider participating in the state and federally funded Denti-Cal program.

- Families call 800-322-6384.
- Providers call 800-423-0507.
- For Denti-Cal application help call 800-422-9495.

California Children's Services (CCS)

CCS provides dental and orthodontic services if they are related to the treatment of a CCS-eligible condition or if the CCS-eligible condition would complicate routine dental care. Services include preventive and restorative services, and general anesthesia when administered in a CCS-approved facility, like Children's Hospital & Research Center Oakland. Call 510-208-5970.

Regional Center of the East Bay (RCEB)

RCEB clients are eligible for services. Call your case manager at 510-383-1200.

Children's Hospital & Research Center Oakland

Children's Hospital provides treatment for baby teeth, preventive care, and treatment under anesthesia for children, usually from birth to age 12, with special needs, uncooperative children, or those who are medically compromised. Call 510-428-3316.

Healthy Families Program

Children enrolled in Healthy Families may receive dental services from a provider that participates in one of Healthy Families' dental plans, including Access Dental, Delta Dental, and Health Net. Call 888-747-1222.

Dental Schools

Most dental schools do not have separate clinics for children with special needs, but serve these children in their general pediatric or advanced general dentistry clinics.

- University of California, San Francisco pediatric dental clinic: 415-476-3276
- University of the Pacific's pediatric dental clinic in San Francisco: 415-929-6550
- University of the Pacific's Dental Care Center in Union City: 510-489-5200



Resource: Special Education

Special education is teaching that is designed to meet the unique needs of children with disabilities. It provides them a free public education in the “least restrictive environment” (the least limiting setting, and closest to being in the home), as mandated by the Individuals with Disabilities Education Act (IDEA). Education for children with disabilities includes independent living skills as well as mainstream school subjects.

What is the Individual Education Plan (IEP)?

The IEP is a planning process. You will meet with the team of specialists working with you and your child. Together, you will develop and put into action a plan of goals and services based on your child’s needs. Children 3 to 18, and up to age 22, if they have not graduated from high school, with the following disabilities, are eligible for an IEP:

- Autism
- Deafness
- Deaf and blind
- Hearing impairment
- Mental retardation
- Multiple disabilities
- Orthopedic impairment
- Other health impairment
- Serious emotional disturbance
- Specific learning disability
- Speech and language impairment
- Traumatic brain injury
- Visual impairment including blindness

How do you begin the IEP process?

You the parent, or a teacher, counselor or other school employee, may request an evaluation for special education services.

The request must be in writing and may be sent to the teacher, principal or the school district’s special education administrative office.

Transportation

Transportation can be a problem for many families. It may affect your ability to get your child to school, to a medical appointment, or around the community for shopping and recreational activities. Programs providing transportation services to families with a special needs child are available.

School Transportation

Your child may be eligible for free transportation to school, therapies and after-school programs, depending on his medical needs and other factors. These services need to be requested and written into the IEP (Individual Education Plan).

Contact information

Call your Special Education Local Planning Area (SELPA) office:

- Alameda/Albany/Berkeley/Emeryville/Piedmont: 510-337-2352
- Oakland: 510-879-8223
- Castro Valley/Hayward/San Leandro/San Lorenzo: 510-537-3000
- New Haven/Newark/Fremont: 510-659-2569
- Dublin/Livermore/Sunol Glen/Mountain House Elementary/Pleasanton: 925-426-9144
- Contra Costa County: 925-827-0949

If your child is a client of the Regional Center of the East Bay or California Children’s Service, your case manager will help you with transportation issues.

If your child is an Alameda Alliance for Health member, you are eligible for transportation services to medical appointments.

With advance notice, Children’s Hospital sometimes offers taxi vouchers for medical appointments to their facilities through the Social Services department. Other agencies, such as the American Cancer Society, also offer transportation to medical appointments related to their mission. This is usually a van staffed by an agency volunteer.





Quick guide to resources

Children's Hospital & Research Center Oakland

As Northern California's only freestanding, independent children's hospital, we are able to provide comprehensive services for children with special needs. Our interdisciplinary approach assures that your child will receive all the care and services he or she needs to live a full, healthy life. Below are just a few of the departments that care for special needs kids. Please ask your pediatrician for a referral or contact our primary care department at 510-428-3226 for an evaluation appointment.

- Audiology, 510-428-3344
- Cardiology, 510-428-3380
- Developmental and Behavioral Pediatrics, 510-428-3351
- Gastroenterology, 510-428-3058
- Nephrology, 510-428-3335
- Neurology, 510-428-3590
- Orthopedics, 510-428-3238
- Rehabilitation Medicine (OT/PT), 510-428-3655
- Speech Language Center, 510-428-3179

Keeping Safe From Injury

Car vests/harnesses/beds/seats

www.adaptivemall.com
www.allegromedical.com
www.angel-guard.com/buy.html
www.columbiamedical.com
www.ezonpro.com
www.safetyangel.com
www.mobility-solutions.com
www.reha-partner.com
www.snugseat.com
www.stores.ebay.com/safety-products-for-families
Prevention Alternatives, 517-927-7731

National Center For The Safe Transportation of Children with Special Healthcare Needs

1-800-755-0912
www.preventinjury.org/specNeeds.asp

Find a car seat check-up in your area

1-800-441-1888; www.safekids.org

Medic Alert bracelet

www.medicalert.org

Medi-Cal

510-639-1000
1-800-541-5555
1-888-999-4772
Medi-Cal application by phone:
510-777-2300
www.medi-cal.ca.gov

Resources

ACCESS/Alameda County Behavioral Health Care Services 24-Hour Hotline 1-800-491-9099

Answers questions about finding and receiving

behavioral health services. They also review Medi-Cal eligibility for mental health services. An interagency referral guide is located at www.first5ecc.org/Documents/fss/Jan%202007%20EPSTDT%20Referral%20Guide.pdf

Contra Costa Health Access Coalition

HAC is an inclusive, broad-based partnership of organizations and individuals whose mission is to improve access to care for all children and families in Contra Costa County.

925-313-6254

Email: lmartine@hsd.cccounty.us

California Children's Services (CCS)

CCS is a state program that pays for specialty healthcare services for eligible children with chronic medical conditions.

Alameda County Public Health Department

510-208-5970
1000 Broadway, Suite 500
Oakland, CA 94607

Contra Costa County

597 Center Ave., Suite 110
Martinez, CA 94553
Phone: 925-313-6100

Family Resource Centers

The network provides parent-to-parent support, information, and referral for families of children from birth to age 22, who have disabilities or special healthcare needs. All staff members are parents of children with special needs.

Family Resource Network—

Alameda County

510-547-7322
5232 Claremont Ave, Oakland CA 94618
Email: Info@frnoakland.org

CARE Parent Network— Contra Costa County

800-281-3023 or 925-313-0999
1340 Arnold Dr., Suite 119
Martinez, CA 94553
Email: careofarc@aol.com

Regional Center of the East Bay

The center is a private, non-profit organization that provides entitlement services for people with developmental disabilities. The East Bay Regional Center serves people of all ages in both Alameda and Contra Costa counties and has no income restrictions.

510-383-1200
7677 Oakport Street, Suite 300
Oakland, CA 94621
www.rceb.org

Early Start Program

The Early Start program provides family-centered early intervention services to eligible infants and toddlers, from birth to age 3, who have, or are at risk for, a developmental disability.

510-383-1355

Special Education Programs

Alameda County: Call your Special Education Local Planning Area (SELPA) office:

Alameda/Albany/Berkeley/Emeryville/Piedmont, 510-337-2352
Oakland, 510-879-8223

Castro Valley/Hayward/San Leandro/San Lorenzo, 510-537-3000

New Haven/Newark/Fremont, 510-659-2569

Dublin/Livermore/Sunol Glen/Mountain House Elementary/Pleasanton, 925-426-9144

Contra Costa County:

West Contra Costa County SELPA, 510-741-2800

Mt. Diablo School District SELPA, 925-682-2000

San Ramon Valley School District SELPA, 925-820-5277

All other areas:

Contra Costa SELPA, 925-827-0949

Dental Care

Most dental schools do not have separate clinics for children with special needs, but serve these children in their general pediatric or advanced general dentistry clinics.

University of California, San Francisco pediatric dental clinic, 415-476-3276

University of the Pacific's pediatric dental clinic in San Francisco, 415-929-6550

University of the Pacific's Dental Care Center in Union City, 510-489-5200

Child Health and Disability Prevention (CHDP)/Denti-Cal

Children with special needs who have Medi-Cal or are CHDP eligible, may receive dental services, including preventive care, through a provider participating in the state and federally funded Denti-Cal program.

- Families call 1-800-322-6384
- Providers call 1-800-423-0507
- For Denti-Cal application help call 1-800-422-9495

Healthy Families Program

Children enrolled in Healthy Families may receive dental services from a provider that participates in one of Healthy Families' dental plans, including Access, Delta Dental and Health Net.
1-888-747-1222

Children's Hospital & Research Center Oakland

Children's Hospital provides treatment for baby teeth, preventive care and treatment under anesthesia for children, usually from birth to age 12, with special needs, uncooperative children or those medically compromised.
510-428-3316



Emergency Information Form

For children with special needs

LAST NAME _____

Developed by: American College of Emergency Physicians and American Academy of Pediatrics

Date completed:	Revised:	Initials:
By Whom:	Revised:	Initials:

Child Information

Child's First Name _____ Last Name _____

DOB ____ / ____ / ____ Gender Female Male Nickname _____

Home Address _____

Parent/Guardian Name _____ Relationship _____

Signature / Consent* _____

Daytime Phone _____ Alternate Phone _____

Emergency Contact Name _____ Relationship _____

Daytime Phone _____ Alternate Phone _____

Primary Language Spoken _____

Physicians

Primary Care MD _____

Emergency Phone _____ Fax _____

Current Specialty MD _____ 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 _____



Diagnoses / Past Procedures / Physical Exam [continued]

Medications	Significant Baseline Ancillary Findings (lab, x-ray, ECG)
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	Prosthese / Appliances / Advanced Technology Devices
5. _____	_____
6. _____	_____

Management Data

Allergies: Medications / Food To Avoid	Why
1. _____	_____
2. _____	_____
3. _____	_____

Procedures To Avoid	Why
1. _____	_____
2. _____	_____
3. _____	_____

Immunization Dates (MM / YY)

DPT						Hep B					
OPV						Varicella					
MMR						TB Status					
HIB						Other					

Antibiotic Prophylaxis: _____	Indication: _____	Medication & Dose: _____
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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 _____



CHILDREN'S HOSPITAL
& RESEARCH CENTER OAKLAND

747 52nd Street, Oakland, CA 94609 • www.childrenshospitaloakland.org

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Phone Numbers & Email

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Observation Chart

Charting you child's daily physical and neurological changes

Child's Name _____ Start date _____ End date _____

Areas to Check:	My child's normal status is:	My daily assessment identified 1 + abnormal findings:	After assessment, I'm concerned and called physician.	My child had an emergency episode; called 911.
Cardiovascular Skin Temperature				
Circulation Skin Color				
Eyes Rash				
Skin Drainage				
Heart Rate				
Nose				
Ears				
Neurological Fontanels				
Seizure Activity				
Verbal skills				
Activity Level				
Respiratory Breathing				
Vent				
Dependent/Tracheotomy/C-pap				
Oxygen				
Musculoskeletal Motor Skills				
Upper body Extremities				
Lower Body Extremities				
Gastrointestinal				
Urinary Stool				
Urine				
Feeding Behaviors/appetite/source				
Behavior Behavior/Attitude				
Sleeping pattern				
Miscellaneous Temperature				
Blood Sugars				
Other				



Observation Chart Guide

Use this guide to help you fill out the Observation Chart

Parent or Guardian: If you identify one or more abnormal findings during your daily assessment, chart the symptoms and physical/neurological changes. Definitely, continue to observe your child closely. Of course, if the symptoms continue, get worse and you become more concerned, contact your child's healthcare provider regarding your concerns.

As you do your daily assessment of your child, here's what you will be watching for:

Cardiovascular / Circulation / Eyes / Skin	Neurological	Respiratory	Musculoskeletal
<ul style="list-style-type: none"> - Change in skin color - Change in skin temp - Rash (describe) - Bruise (where) - Swelling (where) - Changes in heart rate - Peripheral or central line - Pain, bleeding, wound (old wound or surgical site) 	<ul style="list-style-type: none"> - Change in fontanel ("soft spot") size, shape - Persistent headache - Mental confusion, slurred speech - Blurred vision - Pupils changed size - Difficulty swallowing - Lethargy (overly sleepy) - Seizure or increase in seizure activity - Increase in drooling, gagging, or choking - Prior symptoms of shunt failure - Loss of consciousness 	<ul style="list-style-type: none"> - Difficult breathing, out of breath - Audible wheeze (whistling) - Leaning forward to ease breathing - Color change in skin - Retractions (inward movement of muscles between ribs) - Increase in coughing - Decrease in peak flow (spirometer, ex. asthma) - Increase in medication use - Increase in secretions - Color change in secretions - Increase in oxygen use - Vent dependent or tracheotomy 	<ul style="list-style-type: none"> - Unable to move extremity - Change in appearance of extremity (color, shape, size) - Change in sensation of extremity - Increase in pain in extremity - Muscle cramping in extremity - Decrease in movement of extremity
Gastrointestinal / Urinary <ul style="list-style-type: none"> - Residual from last feeding - Nausea, pain, or vomiting (color, consistency, pain) - Increase or decrease in stool (color, consistency, pain) - Increase in urine (color, odor, appearance, pain) - Bleeding (where) - Abdomen distended (hard, bigger than usual) - Enteral feedings, G-tube, Mic-key button - Sunken eyes, dry tears, dry mouth (dehydration) - Any ostomy sites 	Behavior <ul style="list-style-type: none"> - Changes in behavior (school, community, home) - Increase in aggressive and/or self-injurious behavior - Irritability or crying for unknown reasons - Sleeping patterns 	Miscellaneous <ul style="list-style-type: none"> - Blood sugars - Elevated temperatures for greater than 24 hours 	
Include information such as: <ul style="list-style-type: none"> <li style="width: 50%;">• How long he/she had symptoms <li style="width: 50%;">• If change was sudden or gradual <li style="width: 50%;">• What child was doing <li style="width: 50%;">• If you did anything to relieve the symptoms <li style="width: 50%;">• What your intuition is telling you about the symptoms <li style="width: 50%;">• What the nurse/nurse practitioner/physician plan or advise? 			



Starter Kit for Children with Special Needs

Presented by the Trauma Services Department

This Starter Kit for Children with Special Needs is a collaborative project developed by:

Editor-in-Chief, Starter Kit for

Children with Special Needs: Bonnie Lovette, RN, MS, PNP, Injury Prevention Coordinator, Trauma Services, Children's Hospital & Research Center Oakland

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Thanks to a partnership between Kohl's, "Kohl's Cares for Kids" program, and Children's Hospital & Research Center Oakland, Trauma Services that was established in 2005, we are able to provide this Special Needs Starter Kit to families, as well as pediatricians, and agencies and organizations serving the special needs population. This partnership is an example of how working together we can offer hope for a brighter, healthier future for all children in our community.



The Kiwanis Cal-Nev-Ha Foundation established the Pediatric Trauma Program (PIP) in 1994. Children's Hospital & Research Center Oakland was one of the first hospital partnerships that began with the goal of developing projects together to reduce the number of children injured or killed by trauma. The Special Needs Starter Kit is an excellent example of how this collaborative effort benefits all children.

Dreaming up this product began in a 2004 workshop given at Children's Hospital & Research Center Oakland entitled *Safe Transport of Children with Special Health Care Needs*. Workshop facilitators were Bonnie Lovette, RN, MS, PNP, Injury Prevention Coordinator, Trauma Services, Children's Hospital and Barbara Cheatham, MA, Program Specialist, Alameda County Emergency Medical Services, Department of Public Health, and the Alameda County Safe Kids Worldwide Coordinator. We are proud to say that SafeKids Worldwide is one of Children's Hospital's Trauma Service's community partners, sharing our commitment to keep all children safe from injury. We thank SafeKids Worldwide for their invaluable contribution to the kit.



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Design by Children's Hospital & Research Center Oakland Communications department

The information in this kit was compiled by Bonnie Lovette, RN, MS, PNP, Injury Prevention Coordinator, Trauma Services, Children's Hospital & Research Center Oakland.