

A JOURNEY ON A BUSY HIGHWAY

This packet will provide you with resources and information for moving ahead along the road to your child's future. The professionals and parents writing this packet will help you to know you are not alone. Knowledge is power. **You are the most important person in your child's life.** This is a resource for possibilities and the result of many caring people wanting to share their journey on this path.

*"When I gave birth to my first child and was told he could not see and had many other health issues, I felt shock, disbelief and a sensation of being completely overwhelmed. I had at least a thousand questions that I couldn't put into words and I did not know how I could possibly live up to my child's needs. How could I be not only a good parent but a knowledgeable one? Who could I turn to for help? Where do I start? I learned there are others who have walked this path and that there are resources for support. **You will too.**"*
From Judith, parent of Edward.

This packet is designed to help you on your journey with your child. The road signs will help guide you through the fact sheets.



Early Development



Roles and Responsibilities



Importance of Early Intervention/IFSP/Parent Perspectives



Navigating the Special Education System



Definitions of Blindness



Reaching Out Raising a Child with a Visual Impairment: "Myths and Realities"



Gathering Medical History/Medical and Clinical Perspectives



Resources:

- Milestones for Blind or Visually Impaired
- SSI for Children

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Dr. Borchert's website is: www.thevisioncenteratchla.org

Dr. Takeshita's website is: www.drbillfoundation.org

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Navigating the System: SSI for Children

What is SSI? (Supplemental Security Income)

SSI is a Federal income supplement program funded by general tax revenues (not Social Security taxes) and is designed to help people 65, blind and disabled, who have little income and limited resources, providing monthly payments to meet basic needs for food, clothing and shelter. Your child younger than age 18 can qualify if he or she meets Social Security's definition of disability for children, and if his or her income and resources fall within the eligibility limits.

For more information contact your local Social Security Administration Office.

SSI Eligibility Criteria?

- To be eligible for SSI benefits, a child must be blind or disabled
- Under the age of 18.

SSI Criteria for "Disable" or "Blind"

Your child must meet all of the following requirements to be considered disabled and therefore eligible for SSI:

- The child must have a physical or mental condition, or a combination of conditions, that result in "marked and severe functional limitations." This means that the condition(s) must very seriously limit your child's activities. The child's condition(s) must have lasted, or be expected to last, at least 12 months; or must be expected to result in death.
- A child with visual impairment may be eligible if the impairment meets the definition of "Statutory Blindness"

(See Understanding SSI, SSI Eligibility Requirements "Statutory Blindness" 2011 Edition. www.socialsecurity.gov)

Following are some conditions that may qualify:

- HIV infection;
- Total blindness;
- Total deafness;
- Cerebral palsy;
- Down Syndrome;
- Muscular dystrophy;

- Severe mental retardation (child age 7 or older); and
- Birth weight below 2 pounds, 10 ounces.

How does SSI program works for a child?

- ✓ A child may be eligible for SSI benefits as early as the day of birth.
- ✓ A child may be eligible for SSI benefits until age of 18.
- ✓ A child with a visual impairment must meet the definition of blindness in order to be eligible for **SSI Blindness** benefits.

SSI rules about income and resources

To qualify for SSI, your child's income and resources are taken into consideration as well as the income and resources of family members living in the child's household. These rules apply if your child lives at home.

If your child's income and resources, or the income and resources of family members living in the child's household, are more than the amount allowed, the child's application for SSI payments is denied. This means that the value of the things you own must be less than \$2,000 for a single parent or \$ 3,000 for a married couple. The value of your home and car usually does not count and you are allowed to have only one home and one car. Other resources that may not count as income are: burial plot or 401k.

How does "deeming" work for a child?

If the child is under 18, not married and lives at home, some portion of the parents' income and resources may be considered as if they were available to the child. This is called "Deeming Process". Deductions are made from deemed income for parent's and other children living in the home, these deductions are subtracted and the remaining amount is used to decide if the child meets the SSI income and resources requirements for monthly SSI benefits.

(see Understanding Supplemental Security Income SSI Spotlight on Deeming Parental Income and Resources 2011 Edition) www.socialsecurity.gov

Providing information about your child's condition

When you apply for benefits for your child, you will be asked for detailed information about the child's medical condition and how it affects his or her ability

to function on a daily basis. Also, you must give permission for doctors, teachers, therapists and other professionals who have information about your child's condition to send the information to the SSI office.

When to apply? As soon as possible, so you don't lose benefits. Even the first call you make, just to make an appointment to apply will be considered as a filing date.

What happens next?

Once the SSI office has all the information it is sent to the Disability Determination Services in your state for review and to decide if your child is disabled.

When could you receive SSI payments for your child

It can take three to five months for the state agency to decide if your child is disabled. However, for some medical conditions, SSI can make payments right away and for up to six months while the state agency decides if your child is disabled.

SSI disability reviews

Once your child starts receiving SSI, the law requires that a review is conducted regarding your child's medical condition from time to time to verify that he or she is still disabled. This review must be done:

- At least every three years for children younger than age 18 whose conditions are expected to improve; and
- By age 1 for babies who are getting SSI payments because of their low birth weight, unless it is determined their medical condition is not expected to improve by their first birthday, then a review is scheduled for a later date.

Your responsibility as a representative payee

you must report the following:

1. **Submit all** monthly gross wages, by visiting or writing your local Social Security office. Social Security also offers a toll-free automated wage reporting telephone system.
2. If someone **moves in or out** of your household
3. If you **leave the country** for more than 30 days
4. If you are **hospitalized** for more than 30 days

What is a representative payee?

A representative payee *is appointed to manage Social Security funds only.*

Right to Appeal

After you have filed an application for SSI, you will receive a written determination. If you disagree with the initial determination, you may request reconsideration by writing to SSI or by completing Form SSA-561. You have 60 days from the day you receive the initial determination to ask for reconsideration. If you ask for reconsideration within 10 days, you will continue to receive payments until the new decision.

MediCal assistance

If you get SSI, you usually can get medical assistance (Medi-Cal) automatically. For Medi Cal changes you can visit:

<http://www.dhcs.ca.gov/spdinfo>.

In Home Supportive Services (IHSS)

People who get SSI may qualify for IHSS, a program that will help pay for services provided to the child so he/she can remain safely in the home.

For eligibility information please visit www.dss.cahwnet.gov

Food stamps

People who get SSI in California **cannot get food stamps** because the state adds money to the federal SSI payment instead.

However, you may be able to get food stamps:

- While you are waiting for a decision on your SSI application;
- If your application for SSI is denied; or
- If you move to another state.

ACKNOWLEDGEMENT

Myrna Medina, Family Specialist/Parent, California Deaf-Blind Services



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DEVELOPMENTAL CHART WITH MILESTONES

For babies and children who are blind or visually impaired

AGE GROUP	Social & Emotional	Communication	Cognitive	Fine Motor	Gross Motor
Birth to 3 months	<ul style="list-style-type: none"> -Recognizes caregivers voice -Can be soothed by voice or touch -Smiles when played with 	<ul style="list-style-type: none"> -Differentiates cries (has different cries for different wants) -Responds to familiar voices -Reacts to sudden sounds -Ignores certain sounds & attends to others 	<ul style="list-style-type: none"> -Recognizes primary caregiver, may be by voice, touch or interaction -Plays with rattles -Cries when hungry or uncomfortable 	<ul style="list-style-type: none"> -Plays with hands -Uses hands for purposeful action -Plays with toys that produce sound 	<ul style="list-style-type: none"> -Holds head steady while being moved -Lifts head up when on belly -Elevates self by arms when on belly (babies who are totally blind or low vision may not do this until after they roll from back to belly)
4 to 6 months	<ul style="list-style-type: none"> -Initiates request for attention 	<ul style="list-style-type: none"> -Turns toward sound -Makes 3 different vowel sounds -Imitates vocalizations 	<ul style="list-style-type: none"> - Turns toward sounds -Places objects in mouth -Shows preference in play materials -Reaches for object in contact with body 	<ul style="list-style-type: none"> -Reaches for object in contact with body with 1 hand (rather than 2) -Places objects in mouth -Uses pads of fingertips to grasp small objects -Transfers object from hand to hand -Brings object to midline -Pulls objects out of container 	<ul style="list-style-type: none"> -Sits with some support -Rolls from belly to back, from back to belly -Sits alone steadily -Pulls to standing (while holding your hands) -Moves forward through crawling, creeping, or any other method
7 to 9 months	<ul style="list-style-type: none"> -Differentiates between familiar & unfamiliar people -Shows stranger anxiety -Shows fear of separation 	<ul style="list-style-type: none"> -Produces vowel-consonant combinations (ex, ga-ga or ba-ba) -Recognizes familiar sounds or phrases 	<ul style="list-style-type: none"> -Explores different textures -Uncovers toy -Pulls string to activate toy -Searches briefly for object lost from grasp but not in contact with body -Reaches for object based only on sound cue -Places object in container upon request 	<ul style="list-style-type: none"> -Explores different textures -Places object in container -Pulls string to activate toy -Plays pat-a-cake 	<ul style="list-style-type: none"> -Pulls self to sitting position -Pulls to standing position (using furniture) -Sits down -Attempts to walk (while holding your hands) -Moves forward through crawling, or any other method
10 to 12 months	<ul style="list-style-type: none"> -Uses gestures -Cries when caregiver leaves -Begins to enjoy social games like peek-a-boo 	<ul style="list-style-type: none"> -Uses gestures -Responds appropriate to familiar requests -Jabbers expressively -Begins to name things 	<ul style="list-style-type: none"> -Moves or gestures toward you when called -Locates fixed (constant) object (ex. Highchair, table, etc) -Puts many objects in container -Learns that an object exists even if out of sight -Works to solve simple problems -Begins to understand cause/effect 	<ul style="list-style-type: none"> -Places peg repeatedly into hole 	<ul style="list-style-type: none"> -Stands alone -Bends down to pick up object -Walks sideways holding on to furniture -Walks alone (3 steps) -Walks alone with good coordination (5 steps) -Pushes small obstacles out of the way -Walks about house or yard independently

AGE GROUP	Social & Emotional	Communication	Cognitive	Fine Motor	Gross Motor
13 to 15 months		-Anticipates routines in response to a familiar request -Uses 21 words appropriately	-Uses 2 related objects (ex. Strikes drum with stick) -Uses object to perform social action (ex. Brushes hair, puts on necklace, etc.)		-Moves around large obstacle -Walks up stairs with help, down stairs with help
16 to 18 months		-Anticipates routines in response to a familiar request -Uses 2 words appropriately			
19 to 21 months		-Uses 8 words appropriately -Strings 2 words together (ex. "mama bye-bye")			
22 to 24 months	-Imitates caregiver -Plays alongside other children -Asks others when needs help	-Uses 2 & 3 word sentences	-Matches objects -Pays attention to activities longer	- Stacks large objects	-Squats
3 years	-Enjoys helping around the house -Likes to be praised after doing simple tasks -Is aware of people's feelings	-Understands most simple language -Communicates clearly	-Fits shapes into matching holes -Sorts objects -Takes things apart & puts them together	-Uses hands for complex tasks -Copies simple shapes	-Runs, jumps, climbs
5 years	-Plays with other children -Understands rules -Expresses many feelings	-Talks about what he or she has done -Asks many questions	-Follows simple directions & does simple puzzles -Understands counting		-Easily walks backwards -Hops on 1 foot

All children reach developmental milestones at their own pace. There will be a wide range of acquisition of milestones, particularly for children who are blind or visually impaired.

"Your child's vision is a learned and developed skill that requires stimulation and experience. Like learning to walk and talk, children may be able to learn to use their remaining vision more effectively. The visual system involves much more than the eyes. The visual system interacts with the muscles of the body to develop reaching, crawling and walking. The theory is that by performing visual stimulation activities the visual areas of the brain are stimulated to maximize the development of vision."*

RESOURCES

Adapted from: WonderBaby.org This website uses three sources (Developmental Guidelines for Infants with Visual Impairment, Helping Children Who are Blind, and Children with Visual Impairments)

*Taken from Developing Your Child's Vision by Dr. Bill Takeshita, Center for the Partially Sighted.

www.low-vision.org



NORMAL VISUAL DEVELOPMENT

At birth

sees only in black, white, and shades of gray, your baby will look at objects close to his/her face-- particularly faces

1 month:

beginning to see colors, follows moving object to midline, looks intently at faces, eye(s) may occasionally drift inward or outward from proper alignment

2 months:

beginning to be interested in complicated patterns but still prefers faces, sharper visual acuity, attends to objects up to 6 feet away, eyes beginning to move better as a team and follow moving objects, shifting gaze

3 – 4 months:

shows greater interest in looking at primary colors, studies fingers and hands, becoming more sensitive to light, eye movement becoming smoother, following activities in their surroundings, both eyes normally look at the same object, may smile when recognizing familiar faces

5-6 months:

eye-hand coordination developed, reaches and grasps successfully, recognizes favorite toys and/or a bottle at a distance, watches toys fall and roll away, able to move eyes more independently rather than head

For children with normal visual development six months of age is an important milestone to have your child's first eye exam. Even though your baby doesn't know letters on a wall chart, your eye doctor can perform non-verbal testing to assess his visual acuity, detect nearsightedness, farsightedness and astigmatism, and evaluate his eye teaming and alignment.

At this exam, your eye care practitioner will also check the health of your baby's eyes and look for anything that might interfere with normal and continuing vision development. For the most thorough eye exam for your 6-month-old, you may want to seek the services of an eye doctor who specializes in children's vision and vision development.

7-10 months:

notices and touches small bread crumbs or food, recognizes partially hidden objects, recognizes family members by facial features, imitates facial expressions, better at judging distances better, grasps and throws objects more accurately, eyes may be changing color

11-12 months:

far and near acuity is good, binocular vision is stronger, depth perception is good, recognizes pictures, plays hide and seek, scribbles spontaneously

12-18 months:

matches identical objects, points to pictures in a book, scribbles vertically, horizontally and in circular motions, identifies forms

18-24 months:

inspects objects visually, imitates movements of others, increased visual memory, all optical skills smooth, matches color and form

No-Cost Eye Exams for Infants

Recognizing the importance of infant vision development to a child's overall development and enjoyment of life, the American Optometric Association established the InfantSEE program in 2005.

Developed in partnership with The Vision Care Institute of Johnson & Johnson Vision Care, InfantSEE is a public health program designed to ensure that eye and vision care become part of routine infant wellness care in the United States.

Under this program, AOA member optometrists offer a comprehensive infant eye assessment within the child's first year of life at no cost. For more information and to find an optometrist who participates in the program, contact the American Optometric Association at (800) 365-2219 or www.infantsee.org

RESOURCES:

All About Vision, Gary Heiting, O.D.
www.allaboutvision.org

Dr. Lea Hyvarinen, M.D. Pediatric Ophthalmologist,
www.drieahyvarinene.com

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Acronyms

CCS California Children's Services

CDE California Department of Education

CLVT Certified Low Vision Therapist

DDS Department of Developmental Services

FVA Functional Vision Assessment

IDEA Individuals with Disabilities Education Act

IEP Individualized Education Program

IFSP Individual Family Service Plan

LEA Local Education Agency

LRE Least Restrictive Environment

NICU Neo-Natal Intensive Care Unit

O.D. Doctor of Optometry

O.T. Occupational Therapist

O&M Orientation and Mobility Specialist

P.T. Physical Therapist

SELPA Specialized Education Local Plan Area

SLP Speech and Language Pathologist

TBVI Teacher of the Blind and Visually Impaired

VI Visually Impaired

Acronyms Used in Medical Reports

OD Right Eye

OS Left Eye

OU Both Eyes

RTC Return to Clinic

VA Visual Acuity

VF Visual Field

RTC Return to Clinic



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Reaching Out

"Raising a child with a Visual Impairment; Myths and Realities"

Myth

I have done something wrong

Reality

"It's not your fault" Dr. Mark Borchert, Neuro-Ophthalmologist, The Vision Center at Children's Hospital Los Angeles tells the family members of his patients. Children are diagnosed with different types and severity of visual impairment every day and no one is to blame.

Reassurance:

It is natural to wonder what might have caused your baby's vision loss. In some cases, the cause of visual impairment is not known. Other diagnoses may be made more easily. It is natural to want to find a definitive cause for a diagnosis and even to have feelings of guilt. Moving beyond these difficult feelings toward acceptance is a positive message for your child. Together you will learn all the things that can be done to accommodate for a visual impairment.

Myth

It is not fair to burden other people with my feelings and concerns about my child and no one can understand how it feels.

Reality

You are not alone in how you feel. Finding sources of support can positively impact your quality of life and help you find others with similar experiences.

Reassurance:

Finding other parents, or family members, who can relate to the ups and downs and everyday issues involved in raising a child with visual impairment can be very reassuring. There are websites for parents where you can post questions. There may be parent support groups in your area or a professional you know may be able to put you in touch with another parent. You may feel hesitant or nervous at the thought of discussing such personal information, but most parents find that it relieves tremendous stress to share stories with others who have similar real life experiences.

Myth

If my baby does not make eye contact or see me, he or she must not know who I am.

Reality

Your baby or child will know you by your voice, your touch, your smell and the many unique interactions you have together.

Reassurance:

Watch carefully for the cues that indicate your child is “greeting” you: opening eyes wide, changes in breathing, getting still or being more active. This body language is a powerful form of communication that should be encouraged and rewarded with your touch and your words.

Myth

My child is vulnerable and needs more protection than a sighted child.

Reality

Your child with a visual impairment will need as many opportunities to explore and experience the world as any other child.

Reassurance:

Letting your visually impaired child freely explore their surroundings will mean more bumps and bruises for them and more anxiety for you. You will need to be creative in how you structure learning opportunities and always make sure the environment is safe. The result, however, is your child becoming an independent, curious, resourceful and confident young person and adult.

Myth

My child's other senses will be sharper to compensate for their visual impairment

Reality

A child who is blind or visually impaired uses

his/her senses more effectively and with more awareness out of necessity.

Reassurance:

Purposeful, hands-on experiences, real-life objects, tactile information, sensory input and daily routines form the basis of learning for children who do not have functional vision as well as those with some degree of remaining vision.

Myth

Learning depends solely on vision.

Reality

Babies who are blind or visually impaired learn and develop skills in all developmental areas just like their sighted peers.

Reassurance:

Children with visual impairment may be able to learn to use their remaining vision more effectively by taking advantage of everyday opportunities to practice visual skills. The theory is that by performing activities that require visual attention, fixation, perception, etc. within daily routines, the visual areas of the brain are stimulated to maximize the development of vision. Children who are blind learn from special strategies that support a child's development through familiar voices, sounds and favorite toys or objects. These strategies can encourage a child to lift their head, reach out in space and explore their environment through repetition and routine activities that promote language as well as safe, successful exploration.

Myth

I need to become an expert in visual impairment to most effectively help my child.



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Reality

You are your child's best and most natural teacher. Professionals will play an important role but the bond between caregiver and child is the most critical for growth and development.

Reassurance:

Your home environment is the most important and familiar "classroom" for your baby. Here are some suggestions on how to maximize your baby's early learning and visual development at home:

~Talk to your baby so he/she knows when you enter a room. Encourage your baby to find your face or voice and reward him or her with a kiss or hug.

~Moderate or bright lighting and contrasting colors and backgrounds may make it easier for your baby to use their vision. Colored tape around a bottle or cup, goldfish in a black bowl, masking tape along a dark carpet and proper lighting will help encourage visual learning.

~Provide a consistent predictable routine to your baby's day like a good morning song, sharing mealtimes in the bright kitchen or using a fuzzy towel before bath time. The song, the light and the towel will all become cues for your baby, helping him or her internally organize a daily routine.

Myth

If I don't do everything the professionals tell me I will seem like a bad parent.

Reality

You know best what feels right for your child and your family.

Reassurance:

More services are not necessarily better. It is important to find professionals with whom you have mutual respect and a shared viewpoint about what is most beneficial for your child. It is important to ask questions of professionals when something is unclear and to respectfully disagree when you are uncomfortable with something or someone. You will be your child's best advocate until he or she is able to advocate for themselves.

RESOURCES

Texas School for the Blind and Visually Impaired
(tsbvi.edu)

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Tori Schladen, Director Family Resource Project
The Center for the Partially Sighted



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Roles and Responsibilities

"Nothing replaces a human being sharing or translating the information." David, parent

The specialists who work in the field of education are also important members of the team for your child in the Individualized Family Service Plan (IEP)/Individualized Education Program (IEP) Process. These professionals may work in the home, classroom, therapy room/clinic or in your neighborhood. These roles and responsibilities are varied. Each team member has important specialized information to share. Your child's needs will determine who is on the team.

Teacher of the Blind and Visually Impaired (TBVI)

The TBVI holds a specialized teaching credential and has the primary responsibility for specialized instruction and services required to meet the unique educational needs of the student with a visual impairment. These services may be provided in the itinerant model daily or weekly.

Orientation and Mobility Specialist (O&M)

The O&M is credentialed and instructs children with a visual impairment in the development of skills and knowledge that enable

them to travel independently and safely in their environment.

Early Interventionist/Early Childhood Specialist

If your child is younger than 3 years old, your team may include an early interventionist, a professional who is trained to support families of young children with disabilities and has a background in child development.

Classroom Teacher

School age students with visual impairments typically attend a public school and are taught in general education classrooms with their sighted peers or in special day classes. This teacher will work closely with the TBVI to get information about the best ways to teach your child and get his/her class materials in the appropriate medium (braille, large print).

Para-educator

(also called teachers' aides, paraprofessionals) The school aide, or teaching assistant, is sometimes assigned to work with students who are visually impaired under the supervision of the classroom teacher and TBVI. This paraprofessional may be assigned to the classroom or to the individual student who is visually impaired.

Other members of your child's educational team may be a specialist in other areas, depending on his/her individual needs. All team members provide information, assessment and direct services. These team members may, or may not, have experience with children who are visually impaired.

These team members include:

Occupational Therapist (O.T.)

The O.T. is licensed to address a child's sensory/motor skills, development of fine motor skills such as dressing and oral motor skills that may have to do with eating.

Physical Therapist (P.T.)

The P.T. is licensed to work on improving and strengthening your child's gross motor skills through activities such as crawling, sitting, walking and running.

Speech and Language Pathologist-SLP (Also known as Speech Therapist)

The SLP is licensed to address the unique educational needs in the areas of improving communication, particularly language development, concept development along with academic skills, oral motor skills and sensory/motor skills. The SLP may also recommend alternative methods of communication for children with multiple disabilities.

Assistive Technology Specialist

This specialist facilitates and makes recommendations to assess the need for technology.

Certified Braille Specialist (Transcriber)

This specialist holds Library of Congress Certification in Literary Braille for preparing materials in Braille.

Counselor, Psychologist, or Social Worker

These specialists are aware of the unique educational needs of the

student with a visual impairment and the student's family.

Regular or Adapted Physical Education Specialist

This specialist is familiar with specialized or adapted equipment in the area of physical education for students who are visually impaired.

Resource Specialist

This specialist provides instruction and Special Education support services to students across disability areas including students with visual impairments.

Program Specialists

This specialist is especially knowledgeable about program options and services available within the region.

Administrator

The administrator is knowledgeable about the roles of each staff member and provides facilities that are appropriate to meet the unique needs of the student with visual impairments.

RESOURCES

Program Guidelines for Students Who are Visually Impaired, California Department of Education, Sacramento, California 1997

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Navigating the Special Education System

"The road block is you don't know what you don't know." Derek father of Moxie, age 3

A child who receives Special Education is entitled to the same rights as typically developing children: a free, appropriate, public education frequently referred to as FAPE (Free Appropriate Public Education). You will be going through the process of the Individualized Family Service Plan (IFSP) for children birth to three and/or Individualized Education Program (IEP) for children three to 21. Bring support (family members, good friends) with you to the IFSP/IEP meeting to help take notes and ask questions. If, for any reason you are unsure of the services being offered to your child think over the recommendations. Discuss the options then come back and sign for agreement or notify the IFSP/IEP team of areas of disagreement.

Transitioning from IFSP to IEP is a process. During the first three years, sharing your child's successes and concerns with your child's early interventionist may have become

a natural process as you worked together in your home. Once your child leaves a home based program and begins a center based program (or preschool), it will be helpful to continue to seek the same communication with your child's preschool teachers and education specialists, maintaining shared understanding of your child's progress and what to work on. This change in services can be challenging for every parent. Open communication with your child's teacher and/or visits to your child's classroom to discuss your child's progress may help reduce your concerns.

Keep in mind what kind of program/services you visualize for your child. Do these services reflect the way your child learns? Are the outcomes for the IEP realistic? Do they address your concerns? Are they developed by all team members?

What the IEP meeting includes:

- Document must be written within 30 days of the school's identification of the child's disability
- Participation of the child's parents



- Special education and regular teachers including a Teacher of the Blind and Visually Impaired (TBVI)
- School system representative
- Someone who can interpret the evaluation results
- Others with knowledge or expertise about the child (may include a physician for example)
- Documents in the family's native language
- Someone to translate to the family's native language

The IEP is reviewed on an annual basis but can be reviewed upon written request by the parent at any time. The child is re-evaluated every three years.

The physician's role in the IEP involves identifying the medical needs that require accommodation in an educational setting and writing a medical statement to describe the needed accommodations. This should include: 1) A diagnosis in medical and laypersons' terms and 2) A brief description of the medical/visual condition.

Federal law, IDEA (Individuals with Disabilities Education Act), defines "children with disabilities" as individuals between the ages of three and 22 who have one or more of the following conditions: visual impairment (including blindness), multiple disabilities, and many other conditions.

A scenario provided by Carlos, parent of Carlos: *"A parent once shared an idea with me and I'd like to share these thoughts with*

you. When your child has a disability, you may think of it as a journey, your child's journey is on a bus. As the parent you are the driver of the bus. As the driver of your child's bus (journey) you decide where to stop, who is entering and who must exit. You are in control and have the power to take your child where you'd like them to go. Your ability to acquire knowledge is the key to getting your child closer to where you would like them to be."

RESOURCES

Eclips extended CLIPP scenarios CLIPPCASES.org

- Child Advocacy Tool
- Medical Statement Resource
- Educational Services Resources

Handbook on Developing Individualized Family Service Plans and Individualized Education Programs in Early Childhood Special Education by California Department of Education, Sacramento California Early Start,
<http://www.cde.ca.gov/sp/se/fp/documents/eciifspiec.pdf>

2006 Central Directory of Early Intervention Resources

<http://www.dds.ca.gov/EarlyStart/doc/centraldirectory2006.pdf>

Nolo's IEP Guide To Learning Disabilities, 4th Edition, Advocate for Your Child, By Attorney Lawrence M. Siegel, Director of the National Deaf Education Project

ACKNOWLEDGEMENTS

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Gathering Medical History and Preparation for a Doctor's Visit/Medical and Clinical Perspectives

When your child is first seen by a new eye doctor, you can expect the doctor or a member of the staff to ask about your family's history of visual impairment and about your child's birth history or when you first noticed changes in your child's visual behaviors.

Trying to prepare for the visit ahead of time may help. Try to schedule the appointment at a time that is good for your child's schedule. Writing down a list of your questions and concerns can be useful in getting the information you need. If your child is seen by a Teacher of the Blind and Visually Impaired (TBVI) ask them for a report to share with the doctor about visual behaviors at home or school

It is sometimes helpful to bring a favorite toy, or to have a bottle or pacifier on hand. These may help your child feel safer and it is hoped, reduce his or her stress level. It may help you to bring another family member, friend, or your TBVI with you to help ask questions..

*"Always remember that it is not your fault. There are a lot of services and doctors out there to help. You are not alone. Stay positive. Talk to other parents and compare experiences."
Jeremy, father of Jayden*

Who Conducts the Exam?

An appointment with the Pediatric Ophthalmologist can be the most important

decision you make to help you understand the nature of your child's eye condition. If your area does not have a Pediatric Ophthalmologist, than a general Ophthalmologist may be necessary or may assist you in the referral to a Pediatric specialist. An Ophthalmologist is a medical doctor who makes a diagnosis, performs surgery, and treats eye diseases. This professional checks the health of the eyes and tests for visual acuity and visual field, prescribes glasses and medication.

Another important specialist to see your child may be an Optometrist. An Optometrist prescribes glasses, low vision aids (magnifiers) and teaches patients how to use them. The Optometrist is typically seen after the Ophthalmologist. Additionally, an important professional for your child to see is a Pediatric Low Vision Optometrist. An Optometrist can help you understand your child's eye condition, inform the parents how much vision your child has and how to maximize the use of his/her functional vision. .

Upon Exam:

During an exam, an eye doctor may check and measure a number of aspects of your child's vision. These may include the health of the eyes, visual acuity, visual fields, refraction and sometimes eye pressure depending on your child's eye condition.

When parents take their child to an eye doctor, whether an ophthalmologist or optometrist, the experience can be stressful. Here are some helpful hints to ease the tension:

- What is the priority for today's visit?

- What are the next steps? By the end of the visit, you should have a basic idea of what the future will bring. Your doctor will not usually answer to “exactly” what future vision will be, but what to watch for and generally what the next few years will hold.

Medical Language

It's important that you let the doctor be the diagnostician and make his or her own assessment. Remember that every profession has its own specialized language and abbreviations, and medicine is no exception. Please refer to our network website and the resources listed to further guide you:

www.birthtofivevision.org

The Pediatric Ophthalmologist's Perspective by

Dr. Mark Borchert, M.D.

After receiving the news that your infant was born with a visual impairment, it is natural to ask the question "why did this happen to my baby?" While research continues to respond to this question, it is critical that you understand: **It is not your fault.** As a Pediatric Neuro-Ophthalmologist, I would encourage you to seek out a Pediatric Ophthalmologist in your community that is familiar with your child's condition, so that you may learn more about the nature of their impairment. Let the physician direct the history that he or she obtains about your child, but be sure to add any additional information that you think may be important at the end.

Access early intervention services in your community and build a team of early intervention specialists who understand your concerns, help you to better understand your child's needs, and suggest ideas to encourage their development.

Play with your child, and experience the joy of discovering their strengths, as well as those areas that may need more support. Share your observations, and your primary questions with your child's physicians and early intervention team, yet understand that many of your questions may not have direct answers. Time and patience may be the only way to predict the answers you seek. From my perspective, knowing that the wisdom you gain in realizing that you are your child's best advocate will be your most valuable tool in meeting the challenges ahead.

The Developmental Optometrist's Perspective

by Dr. Bill Takeshita, O.D.

“Is there anything that can be done?” This is the most common question asked by parents of children with vision impairment. The answer to this question is “Yes!” The first 5-years of life are the most critical years for the development of a child, including the development of vision. Many children with low vision are delayed in making eye contact, reaching for toys, crawling, or even talking. Fortunately, with the assistance of a team of professionals, many children with low vision make excellent developmental gains.

The first step for parents is to create a team of experts who can help the child with reduced vision. First, the child should have a complete ophthalmologic eye examination by a pediatric ophthalmologist who specializes in the specific condition of the child. It is not sufficient to have the child seen by a general pediatric ophthalmologist. The ophthalmologist may recommend surgery, medications, or other treatments that can improve the vision of the child. Next, the child should be examined by a pediatric low vision



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optometrist or ophthalmologist, preferably one who understands vision development. These doctors can perform special tests to determine how well the child is able to see, regardless of whether the child is able to tell you what they see. By understanding what the child is able to see, parents and therapists will be able to help the child much more effectively as the child grows and develops. There is much that we can do together to ensure that you have the knowledge and resources to maximize your child's development

RESOURCES

Blind Babies Foundation, Oakland, California
94612, 510-446-2229, www.blindbabies.org

Family Connect, www.familyconnect.org

ACKNOWLEDGEMENTS

RESOURCES

Carlos Martinez, Parent Mentor, Blind Childrens Center

Diana M. Dennis, Director of Children's Programs, Therapeutic Living Center for the Blind,

Dr. Mark Borchert, M.D. Associate Professor of Ophthalmology and Neurology, Keck School of Medicine, University of Southern California, Director, The Vision Center, Children's Hospital Los Angeles, University of Southern California.

Dr. Bill Takeshita, O.D., F.A.A.O., F.C.O.V.D., Director of Children's Services, Center for the Partially Sighted, www.low-vision.org



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Navigating the System of California's Early Start Program for Children with a Visual Impairment

Concern about child's vision, what do you do?

If you are the parent/guardian

First speak w/Pediatrician and ask for referral to a **Pediatric Ophthalmologist /Pediatric Optometrist**

If a diagnosis of visual impairment is made, or vision is of concern, you should ask for an assessment with the **Early Start Program** through your **Local Education Agency (LEA)/School District**.

If you are concerned about your child's overall development you can also ask for an assessment with your local **Regional Center**.

Call **1-800-515-BABY** or
www.dds.ca.gov/earlystart

What is the next step?

Child's Evaluation for eligibility and assesment for service planning, Individualized Family Service Plan (IFSP).

Depending on your child's needs, he/she will be assessed by a team of specialists, and eligibility for services will be determined based on diagnosis, risk factors and % of delay.

A Service Coordinator from either the school district and/or the Regional Center will meet with you to review developmental levels, service needs, determine outcomes and develop a written plan, which is called the IFSP.

During this process, your family concerns, priorities and resources will be identified and a referral to other community resources may be necessary, like health services, social services, **Family Resource Centers (FRC), CCS and SSI**

Important Additional Resources -

There are many resources to consider, but these 3 may be the ones you should look into first and consider a priority...

Family Resource Centers (FRC) are most valuable & are available in regional areas. They offer you opportunities to connect w/other parents, provide trainings and education sessions, support groups, and resources to help parent a child with special needs.

California Children's Services (CCS) is a state program that helps children with certain physical limitations, diseases or chronic conditions. CCS covers most problems that are physically disabling or require surgery, medicines, or rehabilitation along with Occupational Therapy & Physical Therapy services for specific eligible conditions.

Supplementary Security Income (SSI) is a federal income program designed to assist blind and disabled people who have little income and limited resources for basic daily living needs. Children under 18 with a disability may qualify.





Definitions of blindness, low vision, partially sighted:

1. Low Vision - is a term used to describe a permanent and significant loss of visual function including either visual acuity (*Measurement*. Assessment of the eye's ability to distinguish object details and shape, using the smallest identifiable object that can be seen at a specified distance: usually 20 ft. or 16 in.), visual field (*Function*. Full extent of the area visible to an eye that is fixating straight ahead. Measure in degrees from fixation), or both. Low vision cannot be fully corrected with conventional glasses, contact lenses, surgery or medication.

Causes of low vision: Low vision may be genetic and begin at birth such as aniridia; it may be developed during the lifetime due to such an eye disease as retinitis pigmentosa; or it may be caused by an accident, such as optic atrophy due to a brain injury. Some eye diseases such as albinism are stable, while others progressively deteriorate, often resulting in low vision followed by total blindness such as retinal detachment.

2. Legal blindness - is when a child's best-corrected visual acuity is 20/200 or less, or there is a reduction in the visual field to 20 degrees or less, in the child's better seeing eye.

3. Partially Sighted - has been used to describe a population of children and adults who have impaired sight and who use vision as their primary learning mode.

4. Total blindness - is when a child has the inability to see; the absence or severe reduction of vision.

5. Eligibility Criteria for the Visually Impaired California Code of Regulations, Title 5, Education section 3030 (d) A pupil has a visual impairment which, even with correction, adversely affects a pupil's educational performance. (for California students only)

RESOURCES

Foundation of Education Second Edition, Volume II, AFB Press

www.cde.ca.gov/re/ph/sm/low_vision.asp

Dictionary of Eye Terminology - Fourth Edition; Barbara Cassin, Melvin L. Rubin, MD, Editor

Program Guidelines for Students for are Visually Impaired, California Department of Education, Sacramento, California

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Diana M. Dennis, Director of Children's Programs, Therapeutic Living Centers for the Blind



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The Importance of Early Intervention

"Our daughter Audrey (18 months) was born with a genetic retinal disease called Leber's Congenital Amaurosis. At 2 months we began to worry because she hadn't started smiling and didn't look into our eyes (something we eagerly anticipated). We saw a pediatric ophthalmologist and the roller coaster ride began. We've learned so much about Audrey's eye condition, her development, parenting, but mostly ourselves. Our hearts have grown tremendously from being her parents and are filled with love and gratitude for the many blessings of our lives, especially having her as our child."

Ashley, mother of Audrey

Understanding the importance of early intervention requires a glimpse at its history. In 1986, additional Federal legislation expanded services to infants and toddlers with the passage of PL 99-457. For the first time infants from birth to three years of age with disabilities were eligible to receive early intervention services from their local education agency (LEA). This legislation created what is known as the Individualized Family Service Plan (IFSP), with the goal to address family concerns in relationship to their child's

development. The spirit of this law as described by a contributor to the legislation is summed up in this statement.

"The IFSP is a promise to children and families—a promise that their strengths will be recognized and built on, that their beliefs and values will be respected, that their choices will be honored, and that their hopes and aspirations will be encouraged and enabled." –Lisbeth Vincent, Ph.D.

Up until the age of three the IFSP is the document that charts parent concerns, provides services and identifies outcomes that support their child's development. As your child approaches three years of age (2 years 9 months) you will begin the process of transition from the Individualized Family Service Plan to an Individualized Education Program (IEP) that addresses your child's particular strengths and the areas of development that may need more educational support.

In the IFSP process a service coordinator will schedule and facilitate a meeting every six months. (In California the service coordinator will come from the Regional Center or the School District.)

What the IFSP meeting includes:

- Both child and family goals-- focuses on the child's and family's natural environment
- Child's current levels of development
- Family's resources, priorities and concerns
- Goals for the child and family with procedures for reaching goals
- Frequency of services
- Documents in the family's native language
- Someone to translate to the family's native language
- Involvement of all team members
- Others with knowledge or expertise about the child (may include a physician for example)

From the Individualized Family Service Plan (IFSP) process your child moves to the IEP. During the transition meeting you will have the opportunity to meet the team of professionals that will guide you through their evaluation of your child's current services. This team will make recommendations for any additional educational assessments to better understand your child's needs. It will be valuable for you to ask that a professional in the field of visual impairment be present on this team. Once these assessments are completed and shared with you, the IEP meeting will be scheduled to review the recommended services and possible

preschool programs that may best meet your child's needs.

A Parent's Perspective From Maria, parent of Victor, a 9 year old child with history of Retinopathy of Prematurity.

"Early Intervention has helped me to understand my child's needs and the services required to meet those needs. As a parent of a child with vision problems I appreciate the reminders from early intervention, that children with low vision have some delays in reaching their developmental milestones. It gives you a sense of belonging- knowing that someone else cares. Early intervention is here to help you."

RESOURCES

"Handbook on Developing Individual Family Service Plans and Individual Education Programs in Early Childhood Special Education" California Department of Special Education, Sacramento 2001
www.scoe.net/seeds/pdf/developing.pdf

"Moving on at Age Three: A Transition Guide for Parents" Harbor Regional Center
www.HarborRC.org

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Maria Zavala, Parent



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Early Development

Early development and learning rely on the visual system for input. As babies begin to interact with people and objects around them, the visual information they gather takes on meaning. Children with visual impairment do not have this complete and continuous source of information and knowledge because what they learn by looking is limited by how much they can see. Supplemental learning for children with vision loss is necessary to help fill the gap between what a child is learning through limited vision and what they need to learn from additional sensory experiences.

Purposeful, hands-on experiences which incorporate tactile information and sensory input form the basis of learning for children who do not have functional vision and are important for all children regardless of their level of vision loss.

For children with impaired but functional vision, it is important to help them learn to use their remaining vision in support of concept and overall development.

As a parent, this means your child who is visually impaired will learn about the world in different and unique ways in order to meet his/her needs. Getting connected to a professional who understands how vision affects development is a critical first step toward assessment of his

developmental needs. Designing individualized intervention strategies will be the next step. Your instinctive parenting skills and the intimate knowledge you have of your child will help you to recognize learning opportunities in everyday activities. Encouraging your child to take an active part in daily experiences will reinforce the most meaningful learning in the most natural environment.

"What really counts in life is the quiet meeting of every difficulty with the determination to get out of it all the good there is" Helen Keller

RESOURCES

Everyday Activities to Promote Visual Efficiency A Handbook for Working with Young Children With Visual Impairments.
Rona Shaw, Ellen Thef, AFB Press

Texas School for the Blind and Visually Impaired, *Basic Assumptions*, 2007

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