

New York City Youth and Vision Loss Coalition

Early Intervention Handbook

NYC Youth and Vision Loss Coalition

Early Intervention: A Guide for Parents with Children who are Blind and / or Visually Impaired

Ages: Birth through 3 years

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Introduction

This handbook results from a collaboration of more than thirty groups of agencies, organizations, and individual stakeholders who came together to gather and make available the much needed information and resources to best serve youth with vision loss in New York City. The New York City Youth and Vision Loss Coalition has assembled these handbooks (General, Early Intervention, Pre-School, School Age, and Transition) to assist young people experiencing vision loss, blindness or multiple disabilities; their parents, caregivers, and guardians; and the professionals and advocates that work with them. We hope to assist you in finding your way through the myriad of complex systems you need to access as your child with vision loss grows and develops into a successful adult. Although your child is still very young, you will be amazed how quickly they grow. Their first twenty-one years will pass by in a flash. Children with vision loss who receive services early are better prepared for a successful future.

First, we will consider the myths and misconceptions about blindness and vision loss. There are millions of people living, functioning, and contributing to society who are blind or have low vision. In New York State a child age 3 or older (or an adult or senior) is considered "legally blind" when his/her visual acuity is 20/200 or less in the better eye with best correction, or his/her field of vision is 20 degrees or less in the better eye. This is the very broad legal definition used to qualify for services from the New York State Commission for the Blind (NYSCB):

www.ocfs.state.ny.us/main/cb/faq.asp#services. However, this definition is not used to determine whether or not a baby or toddler should be assessed for Early Intervention Services. It is recommended that a baby or toddler be evaluated for Early Intervention Services when there is a suspected vision impairment based on gross screening measures or a diagnosed visual impairment that cannot be corrected with treatment including glasses, contact lenses or surgery. You or your pediatrician may notice a potential problem. Visit the NYS Department of Health Early Intervention Services for more information at http://health.ny.gov/community/infants_children/early_intervention for more information.

The first misconception of blindness is that all individuals who are categorized as "legally blind" or visually impaired have no sight whatsoever

or see total darkness. This is not true. Some people who are blind can see light and/or shadows, while others have a good deal of usable vision given proper lighting, proper magnification, high contrast and other accommodations.

One goal of these handbooks is to assist you to better understand that children with visual deficiencies are children first. They want the same things and have the same needs as all children. However, children with vision loss will require alternative means of input to explore and learn about their environment. For example, it is not instinctive when a baby learns to roll over. Rolling over is attempted because the baby sees something in their environment that is just out of reach such as a bottle, ball, stuffed animal, etc. Sighted children have the ability to see the space around them and learn the concepts of space and distance by actions such as pulling their foot to their mouth and reaching for an item that might be at arm's length. When a baby cannot reach an item that is beyond her arm's length, she shifts her weight and gives a push, thus learning to roll over. Babies with low vision or no vision often need some assistance and training in engaging with the environment around them. They may not know the object just beyond their reach is there unless you show them. They can learn how to isolate the sound of an object and learn to roll over to reach the sound. This is only one example of the age appropriate suggestions and resources offered throughout this and the other handbooks to assist you and your child throughout the development stages.

During these early years, your child will join their peers in building the many concepts and skills that will guide them throughout their life's journey. We hope you will read these handbooks as to raise your personal awareness of the needs of your child with vision loss. The first step is to focus on the present needs of your baby or toddler, starting with Early Intervention.

What is Early Intervention?

Early Intervention is a program for babies and toddlers with disabilities and their families. Children must be under the age of 3 years old with an established developmental delay or confirmed disability as defined by the State in one or more of the following areas of development:

- Physical
- Cognitive

- Communication
- Social-emotional
- Adaptive

The Early Intervention Program is operated by the New York State Department of Health, created by Congress in 1986 and has been in effect since 1993. For more information visit the NYS Department of Health at: [www.health.ny.gov/community/infants children/early intervention](http://www.health.ny.gov/community/infants_children/early_intervention).

Children with vision loss, who receive early intervention services, learn techniques and skills that stimulate their curiosity and thrill of learning about the world around them and their immediate environment. Parents and family members can learn techniques and skills that encourage safe exploration, development of other senses, and introduction to tools and equipment to accommodate to the vision loss (and other disabilities if applicable.) Parental and sibling expectations are key to factors in children with vision loss learning new skills or using adaptive techniques. This often makes it easier for parents to understand and accept their child's visual impairment.

Parents or guardians can also make important connections with other families through support groups, on line networking and attendance at family support service programs. Here they learn about assistive technology, equipment, and services available for the child with vision loss. It is very important to build a strong parent/child relationship and reinforce the positive roles of a child with vision loss along with other children in the family.

Process of Early Intervention

The process of Early Intervention begins with you. Should you notice signs of a visual impairment, you can contact your child's pediatrician and they can offer you a referral to an eye care specialist or you can contact the New York State Department of Health directly to request an evaluation to determine your child's eligibility for services. To obtain early intervention services you should start by contacting the Early Intervention Official (EIO) that covers the county you live in. Contacting the EIO will facilitate the opening of a case or update an existing case. There is an Early Intervention Official designated for each county throughout the state. Visit the New York State Department of Health website at

www.health.ny.gov/community/infants_children/early_intervention and, search for “county contacts” for more information and to find services outside of New York City.

The roles of the EIO are:

- Find eligible children throughout the state,
- Make sure children receive an evaluation,
- Appoint an initial service coordinator to help families with their Individualized Family Service Plan (IFSP), and
- Make sure that children and families are receiving the services discussed on their IFSP.

In New York City, the Early Intervention Program is administered by the **NYC Department of Health and Mental Hygiene:**

Gotham Center, CN # 12
42-09 28th Street, 18th Floor
Long Island City, NY 11101-4132
Phone Number: In NYC Dial 311
Outside NYC: 212-639-9675
Fax: 347-396-6928

<http://www1.nyc.gov/site/doh/health/health-topics/early-intervention.page>

Following is the contact information for each county in New York City:

- Bronx (Bronx County)
1309 Fulton Avenue, 5th Floor
Bronx, NY 10456
Phone: 718-410-4110
Fax: 718-410-4480
- Brooklyn (Kings County)
16 Court Street, 2nd & 6th Floor
Brooklyn, NY 11241
Phone: 718-722-3310
Fax: 718-722-77667 or 7766

- Manhattan (New York County)
42 Broadway, Suite 1027
New York, NY 10004
Phone: 212-436-0900
Fax: 212-436-0901
- Queens (Queens County)

90-27 Parsons Blvd., 2nd Floor
Jamaica, NY 11432
Phone: 718-480-2249
Fax: 718-291-1710
- Staten Island (Richmond County)

135 Canal Street, 2nd Floor
Staten Island, NY 10304
Phone: 718-568-2300
Fax: 718-568-2341

In New York City, families of children in the Early Intervention Program will get help from a service coordinator who explains the program, and helps the parent/family select an evaluation agency.

If the evaluation indicates that a child is eligible and in need of the program, an Individual Family Service Plan (IFSP) meeting is held. At the IFSP meeting, a plan is developed with the parent/guardian to help you understand and meet your child's developmental needs.

Early Interventionists (teachers and therapists) will then work with you during times you think are best for you and your child to learn. Early Interventionists look at your daily routines with you. They assist you in finding ways to help your child learn during the usual routine. For more information visit the NYC Department of Health and Mental Hygiene at:

<http://www1.nyc.gov/site/doh/health/health-topics/early-intervention-information-for-families.page>.

The Evaluation

Upon referral you will be assigned an initial service coordinator. The ISC will explain the Early Intervention Program, your rights and responsibilities, and help you locate an evaluation agency.

The evaluation agency you select will complete a multidisciplinary evaluation (MDE). If your child is found to have a substantial delay or diagnosed condition, he/she may be eligible for EI services. A complete evaluation or assessment for an infant or toddler with a visual impairment should include:

- a. Evaluation of each developmental area, i.e., cognition, physical (including vision, hearing, fine or gross motor), social-emotional, adaptive, and communication/ language, with appropriate adaptations made for specific items on the assessment tools that require vision to perform; and,
- b. A complete picture of the child's visual status in order to provide the information needed for development of the Individualized Family Service Plan (IFSP) and program planning.

If however, you suspect or you have been informed that your child may have a vision impairment, it is important that the evaluator you choose be knowledgeable in the field of vision loss. The list of evaluators is long and can be hard to navigate as skills and specialties are not readily available on the easy-to-access websites. Be sure to discuss the possibility of vision loss with the Initial Service Coordinator (ISC) and at the initial consultation with the evaluating agency. The agencies providing evaluation services are also EI service provider agencies bidding for your business: be a smart advocate and do your homework. Talk to other parents with children with vision loss or multiple disabilities.

Requirements for a fair (unbiased) evaluation

The Early Intervention Program has rules to make sure that your child's evaluation is fair.

These include:

- Your child’s evaluation team must use materials and activities that are sensitive to your family’s language. The evaluation must be completed in the “dominant” language of your family if there is limited English proficiency. “Dominant” language means the language you most often use when speaking to your child.
- The cultural background and traditions of your family must be considered in your child’s evaluation. Families raise children using their own cultures and ideals. Your child’s evaluation team must take this into account in deciding what materials to use and describing your child’s responses to the evaluation.
- Your child’s eligibility cannot be based on only one test or procedure. This means that more than one source of information must be used to decide whether your child is eligible, read more at: www.health.ny.gov/publications/0532.pdf.

Individualized Family Service Plan (IFSP)

If your child is eligible for Early Intervention services you, your service coordinator, evaluator, and Early Intervention Official Designee will develop the Individualized Family Service Plan (IFSP).

The Individualized Family Service Plan (IFSP) is a document that specifies and guides the early intervention process for children with disabilities and their families. The IFSP is your tool and the vehicle through which effective early intervention is implemented in accordance with Part C of the Individuals with Disabilities Education Act (IDEA). It contains information about the services necessary to facilitate a child's development and enhance the family's capacity to facilitate and support the child's development. Through the IFSP process, family members and service providers work as a team to plan, implement, and evaluate services tailored to the family's unique concerns, priorities, and resources.

According to IDEA, the IFSP should be written and contain statements of:

- The child's present levels of physical development, cognitive development, communication development, social or emotional

development, and adaptive development.

- The family's resources, priorities, and concerns relating to enhancing the development of the child with a disability;
- The major outcomes to be achieved for the child and the family; the criteria, procedures, and timelines used to determine progress; and whether modifications or revisions of the outcomes or services are necessary;
- The specific early intervention services necessary to meet the unique needs of the child and the family, including the frequency, intensity, and the method of delivery;
- The natural environments in which services will be provided, including justification of the extent, if any, to which the services will not be provided in a natural environment;
- The projected dates for initiation of services and their anticipated duration;
- The name of the service provider who will be responsible for implementing the plan and coordinating with other agencies and persons; and
- The steps to support the child's transition to preschool or other appropriate services.

To view a blank NYC IFSP packet visit:

www.nyc.gov/html/doh/downloads/pdf/earlyint/IFSP-packet-for-printing.pdf

The U.S. Department of Education rules of 1993 require that non-Part C services needed by a child, including medical and other services, are also described in the IFSP along with the funding sources for those services. Services that are not covered by Early Intervention may be covered by health insurance.

The following people will be at the IFSP meeting: the parent, initial service coordinator (ISC), a representative of the evaluation team, the Early

Intervention Official Designee (EIOD), and any person the parent may choose to invite.

At the IFSP meeting you will choose an Ongoing Service Coordinator (OSC), who will work with you to ensure that you, your child, and your family continue to receive the services authorized by the IFSP. This will include regular reviews of the IFSP. You will meet with your OSC every 6 months to review your IFSP, discuss progress, make changes and ensure that all recommendations are being met. [Read more](http://nyc.gov/html/doh/html/mental/earlyint.shtml) at: <http://nyc.gov/html/doh/html/mental/earlyint.shtml>.

Additionally, you can raise any questions with your Ongoing Service Coordinator (OSC) with regard to the services and supports to be provided by the Early Intervention program. Some of the services that may be authorized by the IFSP include:

- family education and counseling, home visits, and parent support groups
- special instruction
- occupational therapy
- psychological services
- service coordination
- nursing services
- social work services
- vision services, teacher of children with vision impairment, and orientation and mobility services
- assistive technology devices and services

Early Intervention services can be provided in various locations, including:

- Home visits or where the child spends most of their day. This can include daycare and child care centers.
- The workplace of the service provider.
- Parent/child groups such as any community activities you may attend with your child.
- Group intervention in which two or more children with vision loss would participate together.

There are six steps in the Early Intervention process.

1. Referral
2. Service Coordination
3. Evaluation
4. Individualized Family Service Plan (IFSP)
5. Service delivery
6. Transition out of Early Intervention

Visit the NYC Health and Mental Hygiene webpage to view or download a copy of the *Parent's Guide to the Early Intervention Program* at: www.health.ny.gov/publications/0532.pdf. This guide offers more detailed information about Early Intervention as well as the processes and expectations for each step of the process.

For more information specific to the early intervention process for babies and toddlers who are visually impaired visit the Perkins Scout webpage at: www.perkinselearning.org/scout/early-childhood-services-children-visual-impairments. The Perkins Scout is a searchable database of national online resources related to blindness and visual impairment. The website mascot, a dog guide named Scout, will help you retrieve the information you're looking for; all of it has been reviewed by Perkins experts and organized for your convenience.

Your Role as a Parent

Learning that your child has vision loss often leads to sadness, concern, disappointment, depression, anger and/or worry. It might feel overwhelming for you and the other members of the family. If these feelings get in the way of your focusing on your child, it is best to seek out counseling so you can learn to accept your child and be able to encourage their positive growth and development. You can receive a referral for counseling through your health insurance, a community mental health clinic, and a vision rehabilitation agency or through a parent network. Helping you, your partner, spouse or co-parent, cope is important since your focus needs to be on best meeting the needs of your child.

We suggest you make a referral for an Early Intervention evaluation and services as soon as you have a diagnosis in hand, as this is the entry point for services. In NYC, you can call 311 and ask to make a referral to the Early Intervention program. In other counties, refer to this list for the referral number:

http://www.health.ny.gov/community/infants_children/early_intervention/county_eip.htm

Additionally, there are many other service provider organizations and programs throughout the city that can help. Agencies and organizations include:

New York State Commission for the Blind (NYSCB) – Children’s Counselors

866- 871-3000

TTY: 1- 866- 871-6000

www.ocfs.state.ny.us/main/cb

- **Manhattan** (All of New York City)
80 Maiden Lane 23rd Floor
NY, NY 10038
Telephone: 212-825-5710
Paul Geraci
Children’s Counselor
212-825-1364
paul.geraci@ocfs.state.ny.us
- **Hempstead** (All of Long Island and portions of NY City)
50 Clinton Street, Suite 208
Hempstead, NY 11550
Telephone: 516-564-4311
Fax: 516-292-7448
Arnie Chapman, MS CRC LMHC
NYSCB-Long Island Children’s Consultant
516-564-4319

Vision Rehabilitation Service Provider Agencies:

Catholic Guild for the Blind

1011 First Avenue, 6th floor

New York NY 10022

888-744-7900

www.archny.org

Helen Keller Services for the Blind

57 Willoughby Street
Brooklyn, NY 11201
718-522-2122
www.helenkeller.org

Lighthouse Guild

West 65th Street
New York, NY 10023
800-284-4422
www.lighthouseguild.org

New York Deaf Blind Collaborative (NYDBC)

Queens College
65-30 Kissena Blvd, KP 325
Queens, NY 11565
718-997-4856
<http://www.qc.cuny.edu/community/nydbc/>

VISIONS/ Services for the Blind and Visually Impaired

500 Greenwich St., 3rd Flr.
New York, NY 10013
T: 212-625-1616
Toll Free: 888-245-8333
F: 212-219-4078
E-Mail: info@visionsvcb.org
www.visionsvcb.org

Blindline® (www.blindline.org) is a NYS information and referral website and center staffed by blind interns (888) 625-1616

Schools

Lavelle School for the Blind

3830 Paulding Avenue
Bronx, NY 10469

www.lavelleschool.org

NY Institute for Special Education

999 Pelham Pkwy
Bronx, NY 10469
718-519-7000
www.nyise.org

New York City Department of Education

400 1st Avenue
New York, NY 10010
212-802-1500
General DOE: www.schools.nyc.gov

NYC Educational Vision Services (EVS) (Ages 3 and up):

http://schools.nyc.gov/Academics/SpecialEducation/D75/related_svcs/Vision

Consumer Organizations

American Council of the Blind of New York (ACBNY)

104 Tilrose Avenue
Malverne, NY 11565
800-522-3303
www.acbny.org

Greater New York Council of the Blind

Faxmode1@earthlink.com

National Association for Parents of Children with Visual Impairments

NAPVI a subsidiary of Lighthouse Guild
West 65th Street
New York, NY 10023
212-769-7819
www.lighthouseguild.org/napvi

National Family Association for Deaf Blind

141 Middle Neck Road
Sands Point, NY 11050
1 800 255 0411
www.nfadb.org

National Federation of the Blind New York State (NFB)

471 63rd Street

Brooklyn, NY 11220

718-567-7821

www.nfbny.org

Parents of Blind Children of NY (POBCNY)

471 63rd Street

Brooklyn, NY 11220

718-567-7821

www.Pobcny.blogspot.com

Finding service providers is only part of the process. It is the responsibility of the parent or guardian to understand what services are needed and how they can positively impact the child and the family. Parents should have frank discussions with your child's pediatrician, eye care specialist, Early Intervention Official at the Department of Health (DOH), and other family members.

Acceptance of your child's disability will open the door to seeking necessary services. The sooner you make that initial contact to determine your child's eligibility for the Early Intervention Program; the sooner services can become a part of your child's development. When the services, supports, and equipment arrive, your child and other family members will begin to understand the functional differences and adaptations needed in your child's life. The words and actions of the people around the child do have a major influence on the child's development and how they view their vision loss. If parents or siblings feel ashamed or try to hide the child or limit their interaction with other people and the world around them, the child with vision loss will suffer. Be prepared for the ignorance, lack of acceptance and misinformation of others. Just as you are learning many things about how to raise a child with vision loss, most people are unaware of the abilities of people with vision loss. Strangers or extended family members can often be unintentionally mean or critical. Learning how to handle these public and family situations with confidence and clarity will be of great benefit to your child with vision loss and siblings.

During their earliest years, children must rely on their parents and family members to be their advocate. Become as informed as you can. Research your child's visual impairment or diagnosis and make every effort to meet other families with children with the same or similar diagnosis. Websites such as the American Foundation for the Blind (AFB) www.afb.org/info/about-us/1 or foundations dedicated to specific diseases or conditions are a good place to start. Other sources of information include: www.familyconnect.org and *Resources for Children with Special Needs* www.resourcesnyc.org. Learn what to expect as your child grows and develops. Ask questions and learn about the devices and technology they will be using. Visit the schools for blind and multi-disabled children, your local pre-school and vision rehabilitation agencies to find out what programs and services are available for you and your child.

Parent's Rights in the Early Intervention Program

The Individuals with Disabilities Education Act (IDEA) makes provisions for parents and guardians within the statute. Starting with early intervention services, you, as the parent or guardian, will be a member of your child's education team and you have rights under the law. Those rights include:

- To agree or not agree to participate in the Early Intervention Program without risking the right to take part in the future.
- To say yes or no to any specific type of early intervention service without risking your right to other types of early intervention services.
- To keep information about your family private.
- To look at and change your child's written record under the Early Intervention Program.
- To be told by your Early Intervention Official about any possible changes in your child's evaluation or other early intervention services before any changes are made.
- To take part – and ask others to take part – in all meetings where decisions will be made about changes in your child's evaluation or services.

- To use due process procedures to settle complaints.
- To be given an explanation of how your insurance may be used to pay for early intervention services.

It is the responsibility of the Ongoing Service Coordinator (OSC) to explain these rights to you and make sure you understand them. Additionally, the OSC should assist you if you feel your rights or the child’s rights have been violated. Remember, IDEA provides specific rights to you and your child. Under the Individuals with Disabilities Education Act (IDEA) your child is entitled to a Free Appropriate Public Education (FAPE). If your child is eligible for early intervention services, NYC must provide them under the law.

What if I have concerns or do not agree with a decision?

- First, discuss your concern or disagreement with your Service Coordinator who can explain your options and rights in further detail.
- You can call the Early Intervention Official Designee (EIOD) or an Assistant Director in the Early Intervention Regional Office at the numbers below:

Bronx:	718-410-4110
Brooklyn:	718-722-3310
Queens:	718-718-480-2249
Manhattan:	718-487-3920
Staten Island:	718- 718-568-2300

- Or, you can call the EI Director of Consumer Affairs, Beverly Samuels, at 347-396-6828.

Due Process

If you still have a concern or disagreement, you can appeal the decision by requesting:

- **Mediation** – This is a way to discuss your concerns and reach agreement with a mediator and the Early Intervention Program. Your Service Coordinator can help request mediation, or you can send a letter to:

Director of Consumer Affairs
NYC Early Intervention Program
Gotham Center #12
42-09 28th St., 18th Floor
Queens, NY 11101
347-396-6828 (Phone)
347-396-8977 (Fax)

- **Impartial Hearing** – This is another way to settle disagreements. It is more formal and carried out by hearing officers who are administrative law judges (ALJs) assigned by the NYS Department of Health. The ALJs make the final decision about the complaint. To request an impartial hearing, you must send a letter to:

NYS Department of Health
Bureau of Early Intervention
Corning Tower, Empire State Plaza
Albany, NY 12237
518-473-7016 (Phone)
518-486-4824 (Fax)

- **Systems Complaints** – This is a way to request that the NYS Department of Health investigate how the Early Intervention Program is working. If you believe that your Early Intervention Official, service provider, or service coordinator is not doing their job under the IDEA as prescribed, (such as not getting you the services listed in your IFSP) you can write to:

NYS Department of Health
Bureau of Early Intervention
Corning Tower, Empire State Plaza
Albany, NY 12237
518-473-7016 (Phone)
518-486-4824 (Fax)

When sending anything by mail:

- ✓ Retain a copy for your own records.
- ✓ Use Certified, Return Receipt Requested.
- ✓ Retain the receipt as proof of sending.

Other Concerns

Through advances in modern medicine, children and families are overcoming many of the difficulties of living with multiple disabilities. In some cases, families of children with multiple disabilities that include a visual disability find that vision services are not provided, or provided by people who are not adequately trained or credentialed in providing vision services. If your child is found to have a visual impairment during the evaluation process, your child should be getting the services of a state Certified Teacher of Children who are Visually Impaired (TVI) and a professionally Certified Orientation and Mobility Specialist (O&M). If the child is not receiving such services, you as the parent have the right to pursue the provider's obligation to rectify the problem.

Additionally, if you find your child is receiving adequate services for his vision impairment but not for other disabilities, the same rules apply. The child should not be denied any of the services or supports needed to learn, adapt and succeed. If the service or support is listed in the IFSP, the child and family have the right to insist that the services are provided. The IFSP is a contract between you, the Department of Health and the early intervention service providers.

For example, a family was receiving extensive early intervention services within their home for a child with multiple disabilities, one of which was blindness. The family was content with the range and scope of services and supports being provided for the numerous other disabilities. However, after some research the family felt that the child should be receiving TVI and O&M services, as was listed on the IFSP.

When the family questioned the provider on the subject of TVI and O&M services, they were informed that the agency did not have a TVI or O&M specialist on staff. However, after continued prodding from the family and further research into their rights, the agency agreed to hire a per-diem TVI/O&M to work with the child. Additionally, the agency had to provide the missed hours of service to the family for the time they did not engage the proper staff to provide the service.

In this particular case, the parents of the child were willing to research the issues and compare the IFSP documented services to the actual services being provided. They made their claim, presented the evidence and

received the services listed on the IFSP. Their child benefited immensely from receiving the appropriate services.

Your child's records

Your child's record includes all written materials developed or used for the Early Intervention Program. Your child's record may include:

- Information gathered as part of your child's referral to the Early Intervention Official (EIO). See Terms and Acronyms below for a description of the Early Intervention Official.
- Screening and evaluation reports and summaries, for example a comprehensive visual assessment or a learning media assessment.
- Your family assessment (if you took part in one).
- Your Individualized Family Service Plan (IFSP) and all documents related to the plan.
- Progress notes and other information about your child's and family's services prepared by early intervention service providers (including your service coordinator).
- Any records about complaints you may have filed.
- All other records involving your child and family.

Early intervention officials, early intervention evaluators, service providers, and service coordinators must keep all information in your child's record confidential. You must give your written permission to allow information in your child's record to be released. There are two types of "releases"¹ that you may be asked to sign in accordance with the DOH regulations:

¹ Source: <http://www.health.ny.gov/publications/0532/step6.htm>

1. A selective release – this type of release requires you to identify the persons who can access the information in your child's record and from whom they can get the information.
2. A general release – this type of release will allow information to be shared with individuals and agencies that will be providing services to your child and family.

Advocacy

Parents want the best for their child. Advocating for your child's rights to education and all available services is very important during the child's early years. As a parent/guardian and caretaker, you are your child's voice. It is important that you learn about and research what is available and educate yourself about what is essential and appropriate for your child's development and future. Seek out and talk with other parents who are going through the same process and share experiences and resources.

It is important for you to understand what services your child is to receive and when and where those services are to be provided. Because the community of people who are blind and vision rehabilitation agencies have been advocating for quality services for many years, there are various groups, organizations, agencies and individuals that can help. Please feel free to visit the Youth and Vision Loss Coalition website at www.visionsvcb.org/visions/nycyouthandvisionlosscoalition for more information and resources.

Brief outline of the laws

Until now, we have mentioned the laws by name and referred to regulations but we have not discussed the laws. The following is a summary of the laws with links to additional information.

The **Individuals with Disabilities Education Act (IDEA)** was created by Congress as the Education for all Handicapped Children Act In 1975. In the 1986 reauthorization Congress provided amendments adding Part C that created the Early Intervention programs for infants and toddlers throughout the nation.

IDEA is the national law that provides children with disabilities access to Special Education Programs. Please see: <http://www.parentcenterhub.org/repository/partb-subpartd/> or the General Youth and Vision Loss Handbook for more information on IDEA.

The New York State Public Health Law

www.health.ny.gov/community/infants_children/early_intervention/index, administered by the DOH, provides all eligible children younger than three years of age the right to receive early intervention services in accordance with their Individualized Family Service Plans (IFSP). Additionally, for residents of New York City, the NYC Department of Health and Mental Hygiene is responsible for the Early Intervention Programs, read more at: .. <http://www1.nyc.gov/site/doh/health/health-topics/early-intervention.page>

Development

A child with visual impairment may have a difficult time developing behaviors that are usually learned through sight without specialized instruction. According to Virginia Bishop's article on Infants and Toddlers with Visual impairment, "the most noticeable delay in development for visually impaired children is in motor areas." This includes posture and movement. Studies have shown that with early intervention these milestone delays have been minimalized in many cases. Bishop suggests that walking or crawling can be delayed six months or more for children in families who do not receive early intervention services. This is a result of the child's inability to see objects beyond arms-length, reducing their motivation to move. According to Bishop, "No other sense sends as much to the brain as quickly as sight."

Some activities that can help you encourage your child's development may include:

- **Reading books:** reading to your child starting at the earliest age helps them develop their vocabulary, imagination and encourages learning skills. If your child is visually impaired, look for books that encourage usage of all their senses especially listening, touching and smelling. There are a variety of books available in braille and large print that can be obtained for your child's enjoyment. It is never too early to introduce large print, braille and audio. As you read the books, describe the pictures on the pages using colors and shapes and have your child feel the braille and other tactile items on the page. Many books for babies

and toddlers emphasize touch, for example *Pat the Bunny*. Some resources for braille and large print books for children are:

- Seedlings Braille Books for Children: www.seedlings.org
 - Braille Super Store: www.braillebookstore.org
 - National Braille Press: www.nbp.org
 - Wonder Baby: www.wonderbaby.org
 - Amazon: www.amazon.com
 - Perkins: www.perkins.org
 - New York Public Library: www.nypl.org
- Take walks with your child outdoors and describe the surrounding area. Have them feel different textures, encourage them to feel and smell the grass, flowers and leaves, play in a sand box, listen for birds or identify other sounds. As your child starts to walk make sure you let them feel a fire hydrant, a mailbox, and a trashcan. Don't take for granted that they will know what it is. If these objects are not easily accessible in your neighborhood, see if your local library or toy store has toy versions for your child to explore.
 - Create arts and crafts projects that include felt, foam, shapes, and finger paint so that your child can feel different textures.
 - Sounds are another good way of stimulating a visually impaired child. Create musical instruments using rice, buttons, and bells. These are entertaining and provide stimulation for infants and toddlers. Animal sounds and other sounds from outside are also intriguing and should be investigated, with appropriate caution. Teach them the sounds of the different animals and introduce them to toys that represent the feel of the fur or shape.
 - Singing, clapping and listening to music is also entertaining and a stimulating activity to share with your infant or toddler. Make music and audiobooks a regular activity.

Learn to play, have discussions, and always make references to things in terms of what they are, what they look like, their shape and size in comparison to something they know and how the child might identify the object. Visit this link for a free download of Virginia Bishop's publication at www.tsbvi.edu/curriculum-a-publications/1051.

The Early Intervention Team

The Early Intervention team is the group that will be providing the services and supports to your child and family as needed throughout the EI process.

The EI team can consist of:

- You (parent/guardian) and your child
- Early intervention official
- On-going service coordinator
- Certified Orientation and Mobility Specialist (O&M) (In Early Intervention, an Occupational Therapist may provide O&M services)
- Certified Teacher of Children with Vision Impairment (TVI)
- Certified Vision Rehabilitation Therapist (VRT) (In Early Intervention a Certified Teacher of of Children with Vision Impairment may provide these services)
- Other professionals including but not limited to licensed occupational therapist, licensed physical therapist, licensed speech therapist/speech-language pathologist, licensed social worker, , etc.

Descriptions of the above Professionals

Orientation and Mobility Specialist (O&M): The word orientation simply means knowing where you are within the environment. Mobility is being able to move/travel from one location to another in a safe and efficient manner. O&M/Early Movement includes: reaching, rolling, scooting, crawling, trunk rotation, transitional movements, standing and eventually walking, etc. Toddlers with vision loss learn how to trail a wall, use a pre-cane device (looks similar to a baby walker), isolate and identify sounds in a room or the outdoor environment, climb stairs with or without help, find a seat and sit in it, identify familiar areas by the furniture, carpeting, flooring or tiles, use sunshine and smell to identify different rooms or areas, etc.

Three primary areas emerge as important within an early intervention O&M program for a child with vision loss. A "formula of purposeful movement" includes three components of program attention: physical readiness, cognitive connection, and motivation invitation: read more at: www.tsbvi.edu/orientation-a-mobility/3228-orientation-and-mobility.

Teacher of Children with Visual Impairment (TVI): Specially trained teachers work with children with visual impairments and their families on pre-academic and academic skills. They assess a child's need for adaptive

reading materials, provide support and instruction in pre-educational and educational settings, and assist the family with school-related issues. A TVI is specially trained to assess for and teach braille.

When working with an infant or toddler who is visually impaired, TVIs develop activities that focus on the development of:

1. Gross motor, orientation and movement skills
2. Fine motor skills
3. Sensory stimulation
4. Cognitive development
5. Communication and early literacy skills
6. Social and emotional development
7. Compensatory skills (e.g. touch, hearing, visual efficiency, etc.)

The TVI may also serve as a facilitator or consultant by observing your child when working with other professionals and pointing out when the vision impairment affects the results and recommending modifications to accommodate the visual impairment: read more at: <http://tsbvi.edu/infants/134-infants/3231-infant-teacher>.

Vision Rehabilitation Therapist (VRT): VRTs specialize in teaching adapted daily living skills. They assess a child's ability to function in everyday activities such as dressing, eating, personal hygiene, and organization, and provide direct instruction in adapted techniques. They work in conjunction with an occupational therapist, orientation and mobility specialist or teacher of children with vision impairment; learn more at: <http://vrt.aerbvi.org>.

Other professionals such as occupational and physical therapists, speech language pathologists, social workers , may also be involved in the assessment and intervention process depending on the strengths and needs of the individual child and family.

Children with many different developmental disabilities, including those who are on the Autism Spectrum, are often found to have visual deficiencies. In cases where the child's visual deficiencies are a result of a Cortical Visual Impairment (CVI), the problem is not always identified during a vision screening. If your child has another disability you should request a referral for a comprehensive vision evaluation that includes a low vision evaluation.

This evaluation should identify any visual deficiencies your child may be experiencing.

Transition to Preschool

When your child turns three, they will be eligible to attend preschool. Your Ongoing Service Coordinator (OSC) will work to assist you throughout this transition as the designated provider agency transfers from the Department of Health (DOH) to the New York City Department of Education Committee on Preschool Special Education (CPSE). The OSC should offer you information on different schools and programs available to your child with vision loss. Your OSC will close out your IFSP after your child starts receiving services through the Department of Education. Refer to this link for information about the differences between EI and CPSE
<http://www1.nyc.gov/assets/doh/downloads/pdf/earlyint/view-of-ei-and-cpse.pdf>

What is an Individualized Educational Program (IEP)?

Although similar in scope, the Individual Educational Program (IEP) differs from the IFSP in many ways. Whereas the IFSP spells out the plan for the family, the IEP focuses on the individual student. This focus will concentrate on the education programs, not necessarily on the child's home life and activities outside of the school but it can include those as well. It is important to know that the IEP is a dynamic document that lives, grows, and changes with the student throughout their primary and secondary education years.

This first IEP will be completed by you, the OSC and the CPSE Administrator. This plan will include all services that your child will require in the school, in classes and to complete schoolwork as independently as possible. Prior to the IEP meeting, you should collect all progress reports and documents pertaining to your child's previously provided early intervention services. You may also want to write down any additional information, questions, or concerns, and compile a list of any assistive technology used by your child to bring with you to the meeting. The IEP process can be overwhelming and you want to ensure that your child's specific needs will be met in the new school setting. If possible, ask someone who knows your child well to come with you to the meeting. Having someone else there that knows your child can help to ensure that all important and necessary information is provided and placed in the

Individualized Education Program (IEP): Read more at <http://schools.nyc.gov/Academics/SpecialEducation/default.htm>. For more information on the Individualized Education Program (IEP) and to download or print one for your personal reference, visit NYSED at www.p12.nysed.gov/specialed/formsnotices/IEP/home.

Resources

Youth and Vision Loss Coalition Members

American Council of the Blind of New York (ACBNY)

104 Tilrose Avenue
Malverne, NY 11565
800-522-3303
www.acbny.org

Art Beyond Sight/ Education for the Blind

589 Broadway, 3rd floor
New York, NY 10012
212-334-8720
www.artbeyondsight.org

Brooklyn Center for Independence of the Disabled (BCID)

27 Smith Street, 2nd Floor
Brooklyn, NY 11201
718-998-3000
www.bcid.org

Bronx Independent Living Services

4419 Third Avenue
Bronx, NY 10457
718-515-2800
www.bils.org

Catholic Guild for the Blind

1011 First Avenue, 6th floor
New York, NY 10022
212-371-1011

www.archny.org

Children's Vision Coalition

119 Washington Ave, 2nd Floor

Albany, NY 12210

877-672-2020

www.cvcny.ny

City Access New York

1207 Castleton Avenue

Staten Island, NY 10310

718-285-6548

www.cityaccessny.org

Dominican College

470 Western Hwy

Orangeburg, NY 10962

845-359-7800

www.dc.edu

Harlem Independent Living Center

289 St. Nicholas Avenue, Suite 21

New York, NY 10027

212-222-7122

www.hilc.org

Helen Keller International

352 Park Avenue, 12th floor

New York, NY 10010

212-532-0544

www.hki.org

Helen Keller Services for the Blind

57 Willoughby Street

Brooklyn, NY 11201

718-522-2122

www.helenkeller.org

Hunter College

695 Park Avenue
New York, NY 10065
212-772-4000
www.hunter.cuny.edu

JP Morgan Chase

277 Park Avenue
New York, NY 10017
212-270-6000
www.jpmorganchase.com

Lavelle Fund for the Blind

307 West 38th Street, Suite 2010
New York, NY 10018
www.lavellefund.org

Lavelle School for the Blind

3830 Paulding Avenue
Bronx, NY 10469
www.lavelleschool.org

Metropolitan Museum of Art

1000 5th Avenue
New York, NY 10028
212-535-7710
www.metmuseum.org

Modest Community Services

88 New Dorp Plaza, Suite 306
Staten Island, NY 10306
718-516-5444
www.modestservices.org

National Family Association for Deaf-Blind (NFADB)

141 Middle Neck Road
Sands Point, NY 11050
1 800 255 0411

www.nfadb.org

National Federation of the Blind New York (NFBNY)

471 63rd Street

Brooklyn, NY 11220

718-567-7821

www.nfbny.org

New York Deaf Blind Collaborative

Queens College

65-30 Kissena Blvd, KP 325

Queens, NY 11565

718-997-4856

www.qc.cuny.edu/community/nydbc/

NY Institute for Special Education

999 Pelham Pkwy

Bronx, NY 10469

718-519-7000

www.nyise.org

Parents of Blind Children of NY

(POBCNY)

471 63rd Street

Brooklyn, NY 11220

718-567-7821

www.Pobcny.blogspot.com

Parent to Parent NY, Inc.

S.I. Special Education Parent Center

Institute for Basic Research

1050 Forest Hill Road

Staten Island, NY 10314

718-494-4872

Fax: 718-494-4805

www.parenttoparentnyinc.org

Readers Digest Partners for Sight

100 South Bedford Road
Mount Kisco, NY 10549
800-877-5293
www.partnersforsight.org

Resources for Children with Special Needs

116 E. 16th Street, 5th floor
New York, NY 10003
212-677-4650
www.resourcesnyc.org

SUNY College of Optometry

33 W. 42nd Street
New York, NY 10036
212-938-4000
www.sunyopt.edu

The New York Community Trust

909 3rd Avenue
New York, NY 10022
212-686-0010
www.nycommunitytrust.org

VISIONS/ Services for the Blind and Visually Impaired

500 Greenwich St., 3rd Flr.
New York, NY 10013
212-625-1616
www.visionsvcb.org

Glossary of Terms and Acronyms

Early Intervention (EI or EIP): The Early Intervention Program is a program for babies and toddlers with disabilities and their families. Children must be under the age of 3 years old with an established developmental delay or confirmed disability as defined by the State.

Early Intervention Service Coordinator (EISC): assists the family with developing the right plan for their child.

Early Intervention Official Designee (EIOD): The EIOD works for the NYC Early Intervention Program. He or she is responsible for making sure that eligible children have an IFSP meeting. At this meeting, you and your team will decide what services and supports are needed to support you family in promoting your child's development. The EIOD also helps parents when they have concerns about Early Intervention services.

Educational Vision Services (EVS): A division of the NYC Department of Education. They provide instruction in utilizing braille, Nemeth Code, large print, optical and non-optical low vision devices and other skills that are necessary to attain academic, social, vocational and life adjustment skills, literacy and acquisition of information using tactile, visual, and auditory strategies. These services may begin when your child is in CPSE.

Free and Appropriate Public Education (FAPE): A required component of IDEA, for children ages 3 through 21, FAPE mandates that school districts provide access to general education and specialized educational services. It also requires that children with disabilities receive support free of charge as is provided to non-disabled students. It also provides access to general education services for children with disabilities by encouraging that support and related services be provided to children in their general education settings as much as possible.

Individuals with Disabilities Education Act (IDEA): Individuals with Disabilities Education Act (IDEA) is the national law that provides children with disabilities access to Special Education Programs prescribed under Federal Law.

Individualized Education Program (IEP): The IEP for children ages 3 through 21, spells out the child's individual needs and goals for the school year while documenting and describing the supports and services the child will receive throughout each school year.

Individualized Family Service Plan (IFSP): An Individualized Family Service Plan (IFSP) for children ages birth to three, documents and guides the early intervention process for children with disabilities and their families. The IFSP is the vehicle through which effective early intervention is implemented in accordance with Part C of the Individuals with Disabilities Education Act (IDEA). It contains information about the services necessary to facilitate a child's development and enhance the family's capacity to facilitate the child's development. Through the IFSP process, family

members and service providers work as a team to plan, implement, and evaluate services tailored to the family's unique concerns, priorities, and resources.

Individualized Plan for Employment (IPE): a written plan which describes the youth's employment goal and the steps the youth will take to achieve that goal. This document is similar to the Individualized Education Program (IEP) the youth might have had during the primary and secondary education process. The IPE is developed in accordance with the interests and abilities of each youth and reflects their choices in identifying an employment goal and the services to be provided to enable them to reach their goals. It may be helpful for the youth, as well as parents and guardians, to learn more about vocational rehabilitation services, different types of employment, and their own capabilities before the plan is written.

New York State Commission for the Blind (NYSCB): The mission of the New York State Commission for the Blind is to enhance employability, to maximize independence and to assist in the development of the capacities and strengths of people who are legally blind beginning at age three through the end of life. (<http://ocfs.ny.gov/main/cb>)

New York City Department of Health and Mental Hygiene (NYCDOHMH): Responsible for the Early Intervention Program in NYC. The DOHMH also offers up to date information about people with disabilities of all ages. (www.nyc.gov/health)

New York City Department of Education (NYCDOE): Responsible for services for children with disabilities aged 3 through 21 as well as free, public education from Pre-K to 12th grade. (<http://schools.nyc.gov>)

New York State Department of Health (NYS DOH): Responsible for the statewide Early Intervention system. Contracts with providers for early intervention service coordination, services, and evaluations.

New York State Office of Mental Health (NYSOMH): promotes the mental health and wellbeing of all New Yorkers. Our mission is to facilitate recovery for young to older adults receiving treatment for serious mental illness, to support children and families in their social and emotional development and early identification and treatment of serious emotional disturbances, and to improve the capacity of communities across New York to achieve these goals. (www.omh.ny.gov)

New York State Office for People with Developmental Disabilities

(OPWDD): The New York State Office for People with Developmental Disabilities (OPWDD) is responsible for coordinating services for more than 126,000 New Yorkers with developmental disabilities, including intellectual disabilities, cerebral palsy, Down syndrome, autism spectrum disorders, and other neurological impairments. It provides services directly and through a network of approximately 700 nonprofit service providing agencies, with about 80 percent of services provided by the private nonprofits and 20 percent provided by state-run services.

(www.opwdd.ny.gov)

Opticians are trained in filling prescriptions for eyeglasses, determining the proper eyeglass frames, and adjusting frames for proper fit. In some states, opticians may be licensed to fit contact lenses. Opticians often work closely within the same location as an optometrist or ophthalmologist, or an optician may have an independent practice.

Optometrist is a Doctor of Optometry (O.D.). To become an optometrist, one must complete pre-professional undergraduate college education followed by 4 years of professional education in a college of optometry. In optometry school, the student receives education primarily about the eyes and receives a comprehensive education regarding the rest of the body and systemic disease processes. The graduate is then eligible to become licensed by a state as an optometrist. Some optometrists also do further postgraduate residency in a subspecialty of optometry such as low vision rehabilitation, primary eye care, geriatric optometry, pediatric optometry, family eye care, contact lenses, sports vision, or vision therapy.

(www.aoa.org)

Ophthalmologist is a medical doctor who is specialized in eye and vision care. In order to become an ophthalmologist, acquisition of an M.D. or a D.O. (doctor of osteopathy) degree is necessary following the completion of college. After 4 years of medical school and a year of internship in general medicine, every ophthalmologist spends a minimum of 3 years in a university and hospital-based residency specializing in ophthalmology. During residency, the ophthalmologist receives special training in all aspects of eye care, including prevention, diagnosis, and medical and surgical treatment of eye conditions and diseases. (www.aaopt.org)

Orientation & Mobility Specialist (O&M): Orientation and Mobility (O&M) specialists teach people who are blind or visually impaired the skills and

concepts they need in order to travel independently and safely, indoors and outdoors, at home, in the school, worksite, classroom, and/or in the community and around New York City. Certification is available through the national Academy for the Certification of Vision Rehabilitation and Education Professionals ACVREP. There currently is no NYS licensure for O&M professionals so it is important to ask if the O&M specialist is certified. (www.tsbvi.edu/orientation-a-mobility/3228-orientation-and-mobility)

Occupational Therapist (OT): Occupational therapists are NYS licensed health care professionals who assist patients of all ages with disabilities and chronic health conditions so they can participate in all activities of daily life as independently as possible. (www.aota.org)

Physical Therapist (PT): Physical therapists are NYS licensed health care professionals who help patients improve or restore mobility and physical function.

PTs assess each individual and develop a plan, using treatment techniques to promote the ability to move, reduce pain, restore function, and prevent disability. In addition, PTs work with individuals to prevent the loss of mobility before it occurs by developing fitness- and wellness-oriented programs for healthier and more active lifestyles. (www.apta.org)

Teacher of Children with Visual Impairment (TVI): TVIs are certified by NYS and provide educational services to students of all ages and ability levels, as well as adaptive skills needed for success inside and outside of the classroom. TVIs plan effective instruction and develop a clear understanding of the unique complex issues facing students with vision loss and their parents. (<http://tsbvi.edu/infants/134-infants/3231-infant-teacher>)

Vision Rehabilitation Therapist (VRT): Vision rehabilitation therapists offer individuals of all ages who are blind or visually impaired instruction, service plans, and equipment they need to lead successful, productive, and independent lives. They provide specialized methods or adaptive techniques for efficient and effective communication, home management, medication management, child care, leisure activities, and coping with the demands of daily living as a child, youth, or adult with vision loss. The broad sphere of communication includes Braille, computers, handwriting, listening and recording technology, low-vision technology, mathematical calculation and keyboarding. Instruction in daily living skills

includes food preparation, personal management, home management, home mechanics, leisure and recreation activities, and orientation and movement in familiar indoor environments.

Certification is available through the national Academy for the Certification of Vision Rehabilitation and Education Professionals ACVREP. There currently is no NYS licensure for VRT so it is important to ask if the VRT is certified. (<http://vrt.aerbvi.org>)

Acronyms:

ACB	American Council of the Blind
ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
ADT	Assistive Technology Device
AFB	American Foundation for the Blind
AYP	Adequate Yearly Progress
CPSE	Committee on Preschool Special Education
CSE	Committee on Special Education
ECC	Expanded Core Curriculum
ECDC	Early Childhood Direction Center
EI	Early Intervention
EIOD	Early Intervention Official Designee
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Plan
IFSP	Individualized Family Service Plan
IPE	Individualized Plan for Employment
NAPVI	National Association for Parents of Children with Visual Impairments
NCEO	National Center on Educational Outcomes
NCLB	No Child Left Behind
NFADB	National Family Association for Deaf-Blind
NFB	National Federation of the Blind
NYDBC	New York Deaf-Blind Collaborative
NYCDOE	New York City Department of Education
NYC DOHMH	New York City Department of Health and Mental Hygiene
NYSCB	New York State Commission for the Blind: previously,
CBVH	NYS Commission for the Blind and Visually Handicapped
O&M	Orientation and Mobility
OPWDD	NYS Office for People with Developmental Disabilities: formally,
OMRDD	Office of Mental Retardation and Developmental Disabilities

OSC	Ongoing Service Coordinator
OT	Occupational Therapy
PT	Physical Therapy
TVI	Teacher of Children with Visual Impairment
VCB	VISIONS Center on Blindness (formerly known as Vacation Camp for the Blind, program of VISIONS)
VRT	Vision Rehabilitation Therapist

Disability Codes

The below coding is most commonly found in the  IEP.

AU	Autism
Deaf	Deafness
DB	Deaf-Blind
ED	Emotional Disturbance
HI	Hearing Impairment
ID	Intellectual Disability
LD	Learning Disability
MD	Multiple Disabilities
OHI	Other Health Impairment
OI	Orthopedic Impairments
SLI	Speech or Language Impairments
TBI	Traumatic Brain Injury
VI	Visual Impairment

