NYC Youth and Vision Loss Coalition

General Handbook

An Introduction to Services and the Service Systems for Youth Who Are Blind, Visually Impaired or Multi-Disabled in New York City

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Preface

This General Handbook and four additional age-specific handbooks have been created to help young people and their parents, caregivers, and guardians gain a better understanding of their vision loss and the services available to meet their needs. Often, parents/guardians are distressed by their child's vision loss and may begin to treat it like the elephant in the room or never discussing it. With this handbook, we hope to assist you in feeling more comfortable speaking on topics from low vision, blindness and multiple disabilities where vision loss is also present. People have different feelings and experiences when describing or coping with vision loss. In this overview, we will provide you with some background to help you better understand vision loss and move forward.

Some children are born with little or no vision, this is considered congenital vision loss or congenital blindness, respectively. Anyone who loses vision after the age of one are considered to have adventitious vision loss. The New York State definition of legal blindness is 20/200 acuity in the better eye with standard correction (while wearing prescription glasses) or less than 20 degrees of visual field in the better eye. The scope or amount of vision loss can be very different in each child. With this definition, two children may function in different ways: one might see nothing, while the other sees nearly everything. The legal definition is based only on acuity and visual field. It is an arbitrary threshold created to establish eligibility for government benefits. It does not consider contrast sensitivity (the ability to see the difference between an object and its background), sensitivity to glare, or daytime versus nighttime vision. Optometrists (ODs) and ophthalmologists (MDs) can measure the extent and type of vision loss, including contrast and glare sensitivity. Vision is also affected by the child's ability to perceive subtle differences and so is unique to that child. A full description of eye care professionals can be found in the section on Terms and Acronyms.

One type of vision loss that can be more difficult to diagnose in young people is **Cortical Visual Impairment (CVI)**. CVI is currently among the fastest growing types of visual impairments. It is a condition that indicates that the visual systems of the brain do not consistently understand and interpret what the eyes see. CVI is caused by a neurological problem affecting the visual part of the brain. One reason CVI is difficult to diagnose is because the young person may be able to read an eye chart during a vision screening. Since the damage is not in the eye itself, the eye will appear "normal" during regular pediatric examinations. This is partly because research has enabled us to understand so much more about the relationship between the eyes and the brain, so the condition is now identified more often. Read more about CVI at: http://tech.aph.org/cvi/?page_id=1175.

All babies and young children should receive a comprehensive vision evaluation prior to and periodically throughout the pre-K and school years. Often it is the parent or guardian who notices that one eye may not focus as well as the other (or "a lazy eye"), frequent blinking, an inability to focus, looking closely at objects, or lack of attention to

bright or flashing lights. Any observations like these should immediately be assessed by an eye care professional.

1. Background

The schools and organizations providing services for those who are visually impaired are aware of the number of young people whose vision is misclassified or who, as a result of multiple disabilities have never received proper vision services. To address this issue, a meeting of interested stakeholders was held by VISIONS/Services for the Blind and Visually Impaired in the offices of The New York Community Trust on November 1, 2013. As a result of that meeting and the generous start-up grants from the New York Community Trust and JP Morgan Chase-Sarah K. de Coizart Trust, the ***New York City Youth and Vision Loss Coalition*** was formed.

The mission of the Coalition is to work toward the improvement of services for young people with vision loss from birth to 21 years, and the dissemination of that information to caregivers. As well as offering assistance in navigating the maze mandated federal, state and city legislation.

The NYC Youth and Vision Loss Coalition membership includes nonprofit agencies, schools, organizations, service providers, consumer groups, individuals, youth with vision loss, and parents/guardians of children with vision loss. These members include but are not limited to:

- American Council of the Blind of New York
- Art Beyond Sight
- Artist/Met Museum Educator
- Bronx Independent Living Services
- Brooklyn Center for Independence of the Disabled
- Catholic Guild for the Blind
- Children's Vision Coalition
- City Access New York
- Dominican College
- Greater NY Council of the Blind
- Harlem Independent Living Center
- Helen Keller International
- Helen Keller Services for the Blind
- Hunter College
- Include NYC,
- Lavelle Fund for the Blind
- Lavelle School for the Blind
- Metropolitan Museum of Art
- National Family Association for Deaf-Blind
- National Federation of the Blind NY

- New York Deaf-Blind Collaborative (NYDBC)
- New York Institute for Special Education
- New York Parents of Blind Children
- New York State Commission for the Blind (NYSCB) Executive Board
- Parent to Parent NY, Inc.
- Staten Island Special Education Parent Center
- Parent to Parent of NYS
- Reader's Digest Partners for Sight
- Staten Island Center for Independent Living
- SUNY College of Optometry
- VISIONS/Services for the Blind and Visually Impaired
- Youth who are blind or have vision loss, and parents of children with vision loss

The Coalition is always happy to welcome new partners!

Another goal of the coalition is to work with the community and provider agencies to create this General Information Handbook and four additional handbooks: *Youth and Vision Loss, Early Intervention, Preschool, School Age and Transition*. The Coalition will continue to research, compile, and make available an extensive list of resources for youth with vision loss and the parents of those youth. It will also continue to reach out to parents, young people, community leaders, additional organizations, and agencies for collaboration and partnership in moving the mission of the coalition forward. The purpose of these handbooks is to provide you, youth with vision loss and caregivers, with the information and resources to assist you in finding your personal path to success. We hope that youth who are visually impaired will live, learn, and understand that success comes from their hard work, values, and their own high expectations for themselves. Please note, handbooks will be updated as new information is gathered and will be available free of charge on the VISIONS website.

2. Brief History of Rehabilitation/Education for the Blind

People who are blind have been receiving rehabilitation services in conjunction with their education in one form or another since 1784 when the first school for the blind opened in Paris, France. Times have changed since the mid-19th century when the movement to open specialized schools for blind children swept this nation.

To aid in the teaching of blind students, in 1879 the American Printing House for the Blind (APH) (www.aph.org) in Louisville, Kentucky was named by the Congress of the United States to be the provider of braille books to schools. This is a service that still provides today, more commonly known by the modern term, Quota Funding; read more at www.aph.org). Today, APH has expanded its service to include not only braille textbooks, but a wide range of adaptive materials and equipment.

The naming of Braille as the universal code sparked the War of the Dots in 1920; it was opposed, primarily, by a group working to create another tactile system entitled New York Point. In spite in of this "war", Braille has remained the standard for tactual reading and writing; to learn more go to www.afb.org/warofthedots/bookasp). Nonetheless, it continues to undergo changes. The most recent change is called UEB (Unified English Braille Code), this uses new codes that are designed to enhance a braille reader's understanding of formatting and font differences in a print document; read more at www.brailleauthority.org/ueb.html.

Schools for blind children were first established in the mid-19th-century. The first two schools established here in New York City were the New York Institute for Special Education (1832) (http://www.nyise.org), and the Lavelle School for the Blind (1904) (http://www.lavelleschool.org). And while these schools are still active today, many more have been established over the years.

Many of the techniques first developed in these schools have been refined over the years and were developed into an Expanded Core Curriculum or ECC. The ECC consists of nine components that encourage and enable blind and visually impaired students to learn the skills and knowledge usually acquired incidentally through visual stimulation and interaction. It has also been modified to be taught in conjunction with the Standard Core Curriculum as students move through the educational system. Additionally, it provides a concrete set of verbal or hands-on instructions with the goal of teaching youth what they cannot see: body language, social interaction, concepts of space and color, as well as sports and physical exercise. The common term referenced within much of the evidence-based research on the ECC is "Incidental Learning" which is the ability to learn from seeing or learning through sight. Visit on the ECC: www.pathstoliteracy.org/expanded-core-curriculum. Read more at: www.eccadvocacy.org.

The nine areas of the Expanded Core Curriculum (ECC) instruction are:

- **Compensatory Skills**
  Skills include concept development and organizational skills as well as communication such as speaking and listening, sign language (if applicable), tactile symbols, braille or print reading and writing, and accessing recorded materials
- **Orientation and Mobility**
  Helping a child to know where they are in space and to move safely, independently, and efficiently in the environment
- **Social Interaction**
  Skills needed to participate actively and appropriately in social situations
- **Independent Living**
  Daily living skills needed to care for oneself independently, including personal hygiene, food preparation, cleaning, clothing care, and money management
- **Recreation and Leisure**
  Promoting the enjoyment of leisure activities, including learning new leisure activities and making appropriate choices about how to spend leisure time

- **Sensory Efficiency**
  Helping students to use all their senses, including functional vision, hearing, touch, taste and smell
- **Assistive Technology**
  Skills to use computers, software and other electronic equipment to function independently and effectively at school, home or work
- **Career Education**
  Encouraging students to explore career options and learn about the world of work
- **Self-Determination**
  Enabling students to become effective advocates for themselves based on their own needs and goals.

3. 1. Rehabilitation Services

In 1913, the New York State Commission for the Blind or NYSCB (http://ocfs.ny.gov/main/cb/Default.asp) was established as New York's registry of people who are blind. The Smith-Fess Act of 1920 expanded the provision of federally funded vocational rehabilitation services from veterans to the civilian population and, because New York State already had the NYSCB in place, its scope was expanded to include providing rehabilitation services as well as remaining the custodian of the eye registry. In its early years, the Commission only served people from ages 18 to 65. ***Today, services are provided from birth to death.***

Starting at age 3, legally blind children are eligible to receive Pre-K services from public and private schools. As they get older, the Commission continues to aid youth in becoming successful adults through rehabilitation services (such as social work, orientation and mobility, and vision rehabilitation therapy), prevocational and pre-college programs, work experience training internships, and short-term after school or summer career awareness programs.

After a child has turned 10, the Commission will begin to use federal dollars to fund students rather than state money. New York and Texas are the only states with approval from the federal Rehabilitation Services Administration to start VR services at age 10 whereas other states start at 14. Because of this, once legally blind youth turn 10, they are assigned to a Vocational Rehabilitation Counselor at their local Commission office. For more information on this topic, visit the Commission's Transition handbook at http://ocfs.state.ny.us/main/publications/pub5100.pdf.

In 1931, the Pratt-Smoot Act was enacted by the United States Congress. It established the federal program of providing books for blind people. It created what was then known as the Division for the Blind of the Library of Congress, now the National Library Service for the Blind and Physically Handicapped or the National Library Service (NLS). In New York State, there are currently two libraries providing

services for blind residents: the New York State Talking Book and Braille Library in Albany (http://www.nysl.nysed.gov/tbbl/) and the Andrew Heiskell Braille and Talking Book Library in Manhattan (https://www.nypl.org/locations/heiskell).

NLS has gone digital with the Bard (Braille and Audio Reading Download) program; you can find them at https://nlsbard.loc.gov/login//NLS. BARD offers people with disabilities full access to a wide range of digitally downloadable books, magazines, music, etc.

VISIONS at Selis Manor located on 23rd Street in Manhattan operates a satellite library service assisting many blind users with downloading books.

3. 2. Assistive Technology

Part of modern-day vision rehabilitation, Assistive Technology, or AT is one of the means available to level the field for youth with low or no vision. AT refers to the tools that allow an individual with vision loss to function beyond his or her visual limits. Just as singers use microphones to amplify their voices through a theater; a visually impaired person uses lenses—a form of assistive technology—to enhance their vision.

For clarity, the tools are described as "low tech" and "high tech." But in all cases, the tools listed below can help students with vision loss better achieve their goals, both personally and academically.

Low Tech: These are typically not computer-based and are meant to help blind and visually impaired youth write, take notes, read books and other hard copy documents. They include slates, styluses, braille writers, hand magnifiers, 20/20 pens (for thicker lines when writing), bold lined paper and standard digital voice recorders.

High Tech: These tools make use of digital technology. They include computers, smart phones, and tablets (including off the shelf commercial or proprietary note-takers). Some of the technologies are speech output, screen-magnification, refreshable braille displays and braille embossers, Optical Character Recognition (OCR) or scanning technology, and video magnifiers.

Parents are encouraged to become acquainted with their child's prescribed technology. Practicing together helps build skills for both while strengthening the parent-child bond and demonstrating the parent's acceptance of the child's vision loss.

Equipment used in school is the property of the DOE (Department of Education) and, therefore, must be returned at the end of each school year. Prior to graduation, however, students are encouraged to meet with their Commission Counselors. This meeting will ensure that the student has continued access to the technology that will help them remain successful throughout postsecondary schooling, training, or employment.

3. 3. Advocacy

The National Federation for the Blind, or NFB (www.nfb.org) was founded in 1940, as an organization that promotes independence for blind people of all ages. The New York State Chapter of NFB has a local affiliate in New York City. They also have a group for parents called Parents of Blind Children. Parents of Blind Children of NY (POBCNY) is an affiliate of the parent's division of the National Federation of the Blind.

The American Council of the Blind, or ACB, (www.acb.org) was established in 1961 as an advocacy organization. They strive to increase the independence, security, equality of opportunity, and quality of life for all blind and visually impaired people. The mission is carried out locally by the New York Affiliate of the American Council of the Blind of New York (ACBNY) (www.acbny.org) and the Greater New York Council of the Blind, a chapter of ACBNY based in New York City.

The National Association of Parents of Children with Visual Impairments NAPVI is an affiliate of Lighthouse Guild. Their main office is located in New York.

National Family Association for Deaf-Blind (NFADB) is the largest national nonprofit organization serving the deaf-blind community.

4. Laws

Because the history of the laws and regulations governing the rights of people with disabilities span many years, we have chosen to focus on the laws from the 1970s to the present. Over that span of roughly 45 years, ground breaking laws were enacted that created equal access to the public and education systems and offered increased opportunities for all people with disabilities.

4. 1. Rehabilitation Act

The Rehabilitation Act of 1973 introduced the well-known Section 504. This part of the act provides for the civil rights of people with disabilities through prohibition of discrimination against qualified individuals by any entity receiving federal funding. Within Section 504, the regulations require all public school districts to provide a Free Appropriate Public Education, or FAPE, to each qualified student, regardless of the nature or severity of their disability. If you, the caregiver, choose a 504 plan, a written plan is developed to ensure the child receives accommodations that will provide full access to the education program). The document assures compliance of Section 504 of the Rehabilitation Act and developed by a team of individuals that may consist of the student with a disability (if appropriate), the student's caregiver, teacher(s), counselor, and the 504 coordinator.

504 Plans ensure that students with disabilities receive timely and appropriate accommodations. It also provides for educators with information about the specific

needs of their students with disabilities and practical strategies they can incorporate into to assist students. Examples of accommodations include but are not limited to wheelchair-accessible facilities, adjustable-height tables, braille or large-print reading materials, and increased time to complete assignments and tests; read more about 504 Plans at: https://ed.gov/about/offices/list/ocr/504faq.html.

4. 2. Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act (1990) had its beginning in 1975 as the Education for All Handicapped Children Act. It is a federal law that governs how states and public agencies provide early intervention, special education, and related services for all children with disabilities. It also addresses the educational needs of children with disabilities from birth to age 18 or 21 in the following specified categories:

1. *Autism*
2. *Deafness*
3. *Deaf-Blindness*
4. *Emotional Disturbance*
5. *Hearing Impairment*
6. *Learning Disability*
7. *Intellectual Disability*
8. *Multiple Disabilities*
9. *Orthopedic Impairment*
10. *Other Health Impairment*
11. *Speech or Language Impairment*
12. *Traumatic Brain Injury*
13. *Visual Impairment*

IDEA—in addition to providing a Free Appropriate Public Education—offers resources for the provisions of, or the lack of, supports and services in accordance with the Individual Education Program, or IEP. However, the ultimate responsibility for knowing and understanding the IEP process falls on the parents or guardians. The IEP

is a legal document that mandates the supports and services while setting goals and milestones for the student to strive for.

You should view the IEP as a contract between the family, the school and the school district. In it, the education system agrees to provide various supports and services. One example is the provision of mobility training by a certified Orientation and Mobility Specialist. This agreed upon service cannot be substituted by a different professional such as a travel trainer or a paraprofessional. Another example is the provision of TVI services at least once a week. If one isn't already on staff, it is the school's responsibility to coordinate with Educational Vision Services (EVS) to employ a TVI. If you believe that the student is not receiving the services listed in the IFSP (Individual Family Service Plan) in Early Intervention or IEP for preschool through high school graduation, it's always best to ask questions. The IFSP/IEP is a powerful tool and can assist you, the student, and appropriate school officials when properly written and implemented. There are organizations that can teach you about the IFSP or IEP and guide you if you feel your child's needs are not being met.

An unfortunate aspect of IDEA is the required categorization of the student into only one of the thirteen disabilities listed above. Often, children have more than one disability. IDEA forces the school, parents and guardians to choose one disability as primary with no opportunity to choose a second or third disability. An example might be a child who has Autism and is blind or has a traumatic brain injury and has low vision. Which disability is more severe? Which disability receives better or more comprehensive services? Who will make the decision as to which disability will be primary? These are questions confronting parents and teachers today. There is one category for multiple disabilities, but that often does not guarantee the receipt of the right supports and services for all the differing needs of the student, especially if vision loss is one of several disabilities.

Students with disabilities who qualify for special education are also automatically protected by Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) (see next section). However, all modifications that can be provided under Section 504 (see the section on Rehabilitation Act of 1973) or the ADA can be provided under the IDEA if included in the student's IEP.

4. 3. Americans with Disabilities Act (ADA)

The Americans with Disabilities Act, ADA, (www.ada.gov) gives civil rights protections to individuals with disabilities that are equal to those provided for individuals based on race, gender, national origin, and religion. It guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation, state and local government services, and telecommunications. Because all young people have the right to a free, public education, it can be considered a government service under the ADA and therefore must be accessible to people with disabilities.

The unfortunate aspect of the ADA and Section 504 is that they are difficult to apply. The enforcement entity for these federal laws is the US Department of Justice, Civil Rights Division. Filing a complaint can sometimes take long periods of time to work its way through the system and this method removes one's right of action to file a lawsuit. A lawsuit is the other means of enforcing the right to avoid discrimination under the ADA, Section 504 or IDEA. A lawsuit may take many months or years to be settled and can be costly. Using the IEP and enforcing it under IDEA may be the best option with regards to education as it was designed with education in mind.

U.S. Department of Justice: The Civil Rights Division, Disability Rights Section offers an extensive question and answer fact sheet with numerous resources for ADA related information at: https://www.ada.gov/childqanda.htm.

5. NY State and City Specific Laws

5. 1. Chapter 377 (2002)

Effective April 21, 2002, Chapter 377 of the Laws of 2001 required every school district and Boards of Cooperative Educational Services, or BOCES, (www.boces.org) to develop a plan to ensure that all instructional materials used in schools of the district—or in a BOCES program—are available in an alternate format for every disabled student, in accordance with his or her individual needs, at the same time that such materials are available to non-disabled students. The plan must include a procurement policy that ensures that preference in the purchase of instructional material the school has selected for its students is given to those vendors who agree to provide such material in alternate formats.

5. 2. Section 219 (2004)

Section 219 is an act to amend the education law in relation to instructional materials for students with disabilities. This law concerns disabled college students and the formats they use to access printed materials. These amendments set forth the requirement that the college make available any and all print material being used within all classes in alternate formats. The college's accessibility office can assist in meeting each student's individual needs. For example, students can work with this office by acquiring the syllabi to their classes as early as possible and providing the office with a list of required texts. They will have resources for providing the books in alternative formats.

See Chapter 219 NYSED law at:
http://www.p12.nysed.gov/specialed/publications/persprep/chap219.htm

5. 3. Blind Student's Literacy Rights and Education Act (1999)

The Blind Student's Literacy Rights and Education Act requires the Department of Education to make provisions for instruction in braille and the use of braille unless the IEP team determines, upon evaluation of the child, that such instruction is not appropriate. Additionally, it sets standards of competency and instruction for the blind or visually impaired child. Finally, it requires teachers certified in the education of blind and visually impaired children to demonstrate competence in reading and writing braille. The passage and the implementation of this law into the New York State education laws are consistent with IDEA as stated by Melody Musgrove, Ed. D and Michael K. Yudin, the Director of Office of Special Education Programs and Acting Assistant Secretary for Special Education and Rehabilitative Services respectively, in their June 19, 2013 "Dear Colleague" Letter. Read the letter at: https://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/guidance-on-fape-11-17-2015.pdf

This law requires that braille be taught to students who are blind unless deemed inappropriate after a full assessment of the student's needs and ability has been considered.

5. 4. Goals and Expectations (Age group specific handbooks)

As stated above, this handbook is the introduction to four additional handbooks that will provide information and perspectives on the educational and developmental milestones and goals for youth with vision loss. In the four additional handbooks, we provide parents, guardians, and young people with useful information on agency services and how these services can be accessed. Consumers or workers within the field of blindness are providing this information. They know the system firsthand. Your questions may not be the same as the ones included in the handbooks, but we hope that sharing this background information will help you move forward knowing that you are not alone, and that help is available.

6. Resources

In doing the research for the handbooks, we found information that was published less than a year ago but already out of date. And, although we have done our due diligence to provide the latest data and resources available, we cannot guarantee the accuracy of its information. Therefore, whenever possible, we have made every attempt to include a webpage or URL address providing you with access to our source. As you find updated or more accurate information, please let us know so that we can update the handbooks.

6. 1. Government Agencies

Below are government agencies that provide funding for community services for people who are legally blind or with functional vision loss.

New York State Commission for the Blind (NYSCB)
http://ocfs.ny.gov/main/cb/

NYSCB was established in 1913 to create and retain a list of blind people in New York State and to provide rehabilitation services for blind persons seeking employment. NYSCB's present day mission is to assist and ensure that the quality of life for New York State residents—ages 3 and older—meet the criteria of legal blindness. Their offices are listed below:

Manhattan
80 Maiden Lane 23rd Floor
New York, NY 10038
Telephone: (212) 825-5710
Serves all five boroughs (VR only)

Hempstead
50 Clinton Street, Suite 208
Hempstead, NY 11550
Telephone: (516) 564-4311
Fax: (516) 292-7448
Serves: Nassau, Suffolk, Queens (VR and Independent Living Only)

Harlem
163 West 125th Street, Room 209
New York, NY 10027
Telephone: (212) 961-4440
Serves: Manhattan and the Bronx

Queens Outstation
Telephone: (718) 557-8871

Adult Career and Continuing Education Services — Vocational Rehabilitation (ACCES-VR)

ACCES-VR, formerly known as VESID, provides vocational rehabilitation services to prepare people with disabilities for employment. Individuals must apply and be found eligible in order to receive services from the agency. Your child's Transition Linkage Coordinator * (TLC), Transition Counselor, Guidance Counselor or other school personnel should help them apply to ACCES-VR if and only if they are not entering NYSCB as a registered consumer of services.

ACCES-VR offers a variety of programs to help students prepare for employment including job training, payment for post-secondary education, supportive employment, and competitive employment. In addition, ACCES-VR can help your child develop independent living skills. Sheltered employment (also known as sheltered workshop) under a 14c certificate from the Department of Labor is a placement of last resort according to federal law. Sheltered workshop placements are permitted to pay less than minimum wage. For more information, visit: http://www.acces.nysed.gov/vr (or the NYS Department of Labor website (see below.)

Department of Labor (DOL)

The mission of the New York State Department of Labor is to protect workers, assist people who are unemployed, and connect job seekers to jobs. The Department of Labor administers state and federal laws and regulations. Learn more about the DOL at: https://www.labor.ny.gov/home.

New York City Department of Health

NYCDOH is responsible for public health, issuing dog licenses, birth and death certificates. They also offer up to date information affecting people with disabilities. Visit the NYCDOH website at www.nyc.gov/health.

New York City Department of Education

NYCDOE offers free, public education from Pre-K to 12th grade; the NYCDOE website can be found at http: schools.nyc.gov/default.html.

New York State Office of Children and Family Services (OCFS)

http:ocfs.ny.gov/main/

OCFS is dedicated to improving the integration of services for New York's children, youth, families, and vulnerable populations by promoting their development; and to protecting them from violence, neglect, abuse and abandonment. The agency provides a system of family support, juvenile justice, childcare services, and child welfare services that promote the safety and well-being of children and adults. Among the operating principles across all program areas are that services should be developmentally appropriate, family-centered, family-driven, community-based, locally responsive, and evidence and outcome based.

OCFS is responsible for programs and services involving foster care, adoption and adoption assistance, child protection services including operating the Statewide Central Register for Child Abuse and Maltreatment, preventive services for children and families, services for pregnant adolescents, and protective programs for vulnerable adults. OCFS is also responsible for the administration and oversight of the functions performed by the New York State Commission for the Blind. OCFS coordinates state government responses to the needs of Native Americans on reservations and in communities.

The agency provides oversight and monitoring of regulated child care (family day care, group family day care, school-age child care and day care centers outside of

NYC), legally exempt child care, child care subsidies, child care resource and referrals, the Advantage After School Program, and provides services and programs for infants, toddlers, preschoolers, and school-age children and their families.

New York State Office of Mental Health (OMH)

New York State has a large, multi-faceted mental health system that serves more than 700,000 individuals each year. The Office of Mental Health (OMH) operates psychiatric centers across the State, and regulates, certifies and oversees more than 4,500 programs which are operated by local governments and nonprofit agencies. These programs include various inpatient and outpatient programs, emergency, community support, and residential and family care programs.

For questions about mental health services, to find a mental health service provider, or to make a complaint, call OMH Customer Relations toll-free at 1 (800) 597-8481 or visit: http: www.omh.ny.gov/index.html.

New York State Office for People with Developmental Disabilities (OPWDD)

www.opwdd.ny.gov

The New York State Office for People with Developmental Disabilities, or OPWDD, is responsible for coordinating services for more than 126,000 New Yorkers with developmental disabilities, including intellectual disabilities, cerebral palsy, Downs 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 by state-run services.

Supports and services, which include Medicaid funded long-term care services such as habilitation and clinical services, as well as residential supports and services, are primarily provided in community settings across the state. Largely because of intensive treatment needs, about 1,200 people (down from approximately 30,000 in the 1970s) continue to reside in institutional settings such as developmental centers, secure facilities, and residential schools for children jointly operated by OPWDD and the New York State Education Department. In addition to these Medicaid services, OPWDD also provides New York State-funded family support services, which are designed to assist families in providing care for their loved ones who live full-time in their family home, and employment supports, which include ongoing job coaching, job matching, and vocational training.

Social Security Administration (SSA)

www.ssa.gov

1(800) 772-1213 (TTY 1-800-325-0778)

Social Security delivers a broad range of services online at (www.socialsecurity.gov) and through a nationwide network of over 1,400 offices that include regional offices, field offices, card centers, tele-service centers, processing centers, hearing offices, the Appeals Council, State and territorial partners, and Disability Determination Services.

Children from birth up to age 18 may get Supplemental Security Income (SSI) benefits. They must be disabled and have little or no income and resources. Social Security has a strict definition of disability for children: The child must have a physical or mental condition that very seriously limits his or her activities; and the condition(s) must have lasted, or be expected to last, at least 1 year or result in death. Learn more at: http: www.ssa.gov/disability/disabilitystarterkitschildeng.htm.

6. 2. NYC Vision Rehabilitation Nonprofit Service Providers

Catholic Guild for the Blind
1011 First Avenue, 6th Floor
New York, NY 10022
T: (212) 371-1011
www.archny.org

Helen Keller Services for the Blind
57 Willoughby Street
Brooklyn, NY 11201
T: (718) 522-2122
F: (718) 935-9463
E-Mail: info@helenkeller.org
www.helenkeller.org

Lighthouse Guild International
15 West 65th Street
New York, NY 10023
T: (212) 769-6200
Toll Free: (800) 284-4422
www.lighthouseguild.org

VISIONS/ Services for the Blind and Visually Impaired
500 Greenwich St., 3rd Fl.
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- A NYS information and referral website and center staffed by blind interns (888) 625-1616

National Association of Parents of Children with Visual Impairments (NAPVI): NAPVI, a nonprofit, national membership organization established in 1980, helps parents find information and locate resources for their children who are blind or visually impaired and who may have additional disabilities. They advocate locally and on a national level for

the resources necessary to educate children with vision loss. Learn more at: www.lighthouseguild.org/napvi

Parents of Blind Children of New York

The POBCNY is a parent advocacy group working to improve the lives of blind children within the State of New York. Their mission is to elevate the quality of education for blind children, to affect their children's access to services, to create opportunities in theater and the arts, in sports and recreation and to raise the level of expectations that those around them have of their children. The children served vary in their degree of vision and often have additional disabilities. Learn more at: www.pobcny.blogspot.com

6. 3. 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.catholiccharitiesny.org

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

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
https://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 (NYDBC)
Queens College
65-30 Kissena Blvd, KP 325
Queens, NY 11565
(718) 997-4856
http/: 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
http://parenttoparentnys.org/offices/new-york-city/
http://parenttoparentnys.org/offices/long-island/

Readers Digest Partners for Sight
100 South Bedford Road
Mount Kisco, NY 10549
(800) 877-5293
www.partnersforsight.org

SUNY College of Optometry
33 W. 42nd Street
New York, NY 10036
(212) 938-4000
www.sunyopt.edu

VISIONS/ Services for the Blind and Visually Impaired
500 Greenwich St., 3rd Fl.
New York, NY 10013
(212) 625-1616
www.visionsvcb.org

6. 4. Books and Literature

National Library Services (NLS)
www.loc.gov/nls

Andrew Heiskell Library
www.nypl.org/locations/heiskell

Learning Ally
www.learningally.org

Bookshare
www.bookshare.org

Audible
www.audible.com

6. 5. Tools and Equipment for Living

American Printing House for the Blind (APH)
www.aph.org

Independent Living Aids
www.independentliving.com

MaxiAids
www.maxiaids.com

LS&S
www.lssproducts.com

General Resources

American Foundation for the Blind
Information, publications, training webinars, directory
www.afb.org

Blindline
www.blindline.org
(888) 625-1616

Vision Aware website
www.visionaware.org

7. Glossary of Terms and Acronyms

Early Intervention (EI): 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.

Educational Vision Services (EVS): part 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, and literacy and acquisition of information using tactile, visual, and auditory strategies.

Free and Appropriate Public Education (FAPE): a required component of IDEA, 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): the national law that provides children with disabilities access to Special Education Programs prescribed under Federal Law.

Individualized Education Program (IEP): the IEP 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): 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 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 or 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 NYSCB is to enhance employability, maximize independence and assist in the development of the strengths and capabilities of legally blind people of all ages. (www.ocfs.ny.gov/main/cb)

New York City Department of Health (NYCDOH): responsible for public health, issuing dog licenses, and birth and death certificates. They also offer up to date information for people with disabilities. (www.nyc.gov/health)

New York City Department of Education (NYCDOE): Offers free, public education from Pre-K to 12th grade. (www.schools.nyc.gov)

New York State Office of Mental Health (OMH): promotes the mental health and wellbeing of all New Yorkers. Their mission is to facilitate recovery for 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): responsible for coordinating services for more than 126,000 New Yorkers with developmental disabilities, including intellectual disabilities, cerebral palsy, Downs 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 by state-run services. (www.opwdd.ny.gov)

Optician: a person 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 may also have their own independent practice.

Optometrist: 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 optometrist 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 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. There is one school of optometry in NYS located in New York City on West 42nd Street, SUNY College of Optometry. (www.aoa.org)

Ophthalmologist: a medical doctor who specializes 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 eye M.D. receives special training in all aspects of eye care, including prevention, diagnosis, and medical and surgical treatment of eye conditions and diseases. (www.aao.org)

Orientation & Mobility Specialist (COMS): 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, at a worksite, in a classroom, and/or in the community. 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.teachingvisuallyimpaired.com/orientationmobility-specialist.html)

Occupational Therapist (OT): NYS licensed health care professional 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): NYS licensed health care professional who help patients improve or restore mobility and physical function. Physical therapists 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, PT'S 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)

Substantial Gainful Activity (SGA): a term used by the federal Social Security Administration (SSA) defined as: A person who is earning more than a certain monthly amount (net of impairment-related work expenses) is ordinarily considered to be engaging in SGA. The amount of monthly earnings considered as SGA depends on the nature of a person's disability. The Social Security Act specifies a greater SGA amount for statutorily legally blind individuals. Federal regulations specify a lower SGA amount for non-blind individuals. Both SGA amounts generally change as a reflection changes in the national average wage index.

Teacher of Children with Visual Impairment (TVI): certified by NYS. They 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. (www.teachingvisuallyimpaired.com/teacher-of-students-with-visual-impairments.html)

Vision Rehabilitation Therapist (VRT): 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, leisure activities, and coping with the demands of daily living as a child, youth, or adult with vision loss.

They teach a broad sphere of communication including braille, adapted computers and software, handwriting, listening and recording 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. VRT's reinforce the use of low-vision technology prescribed by the OD or ophthalmologist.

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's so it is important to ask if the VRT is certified.

7. 1. 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 Developmental Center

EI - Early Intervention

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

NYCDOE - New York City Department of Education

NYDBC - New York Deaf-Blind Collaborative

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 People with Mental Retardation and Developmental Disabilities

OT - Occupational Therapy

PT - Physical Therapy

SGA - Substantial Gainful Activity

SSA - Social Security Administration

SSDI - Social Security Disability Insurance

SSI - Supplemental Security Income (SSA program)

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

7. 2. Disability Codes

The below coding is most commonly found in the legal documents: the IFSP and 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

8. Appendix

8. 1. NYS Commission for the Blind 1913-2013

Below is a time line compiled by Ms. Susan Loeb of the New York State Commission for the Blind (NYSCB) in 2013 as she researched the history of the New York State Commission for the Blind (NYSCB) in preparation of the Centennial Celebration.

HIGHLIGHTS IN THE HISTORY OF THE NYS COMMISSION FOR THE BLIND 1913-2013

Preliminary Investigations on Blindness

- 1903- Governor Benjamin B. Odell, Jr., signed a bill providing for a three-member commission to investigate "the condition of the adult blind in New York State." The Commission study found available records unreliable and that there was a regrettable amount of unnecessary blindness.

- 1906- A second investigation committee was mandated by law to make a complete census of the blind in New York State. In the taking of this census, the Massachusetts definition of blindness was used. All persons were termed blind who..."with the aid of glasses yet were not able to distinguish form or color, to count fingers within one foot of the eye or to read writing or ordinary print." In the census, 5,308 persons were identified as blind in New York State. A recommendation was made that a Commission for the Blind be established.

- 1913- The New York State Commission for the Blind was established on April 30, 1913. It was comprised of a five member non-salaried board of commissioners. The original board had administrative functions and had the authority to appoint staff and fix their compensation. The first office of the New York State Commission for the Blind was opened on September 15, 1913 at 105 West 40th Street, New York City.
    - Mandated activities of the commission for the Blind under the 1913 Commission Act (chapter 415 of the laws of 1913) included:

1. Maintenance of a register of the blind in New York State.

2. Maintenance of a bureau of information and industrial aid, the object of which was aiding blind persons in finding employment and teaching them trades and occupations which they would be able to follow in their homes and disposing of the products of home industry.
3. Inquiry into the causes of blindness, and inauguration and cooperation in preventive measures.
4. Investigation of the needs of blind person.

Permissive activities of the Commission for the Blind included:

1. Establishment of training schools and workshops for the employment of blind persons and payment of training and maintenance fees.
2. Amelioration of the condition of blind persons by the promotion of visits among them and teaching them in their homes.

The Commission for the Blind Community Services and Vocational Rehabilitation Services programs, which were developed later, had their earliest beginnings in 1913. Vending Stand Service also had its beginning in 1913, when the Commission field agent set up a blind man in business as a street corner newsvendor and the Production and marketing service when the Commission agreed to take over the home industry department of the MATILDA ZIEGLER MAGAZINE. This function provided furnishing to blind people in their homes, at cost, such material as could be made into saleable objects.

- 1915- The Commission invited a group of well-known ophthalmologists to act as its advisory council in the formulation of policies related to prevention of blindness.
    - Workshop opportunities for blind persons in various parts of the State were enhanced by the Commission through assistance given to local agency industrial centers for the blind.

- 1916- The Commission organized an eye clinic program at Sing-Sing Prison. It continued to operate under the auspices of the commission until 1920 when responsibility for this function was passed onto the prison's medical staff.
    - The presently constituted Eye Health Service had its beginning in January of 1916 when two Social Service Nurses were added to the Commission staff for prevention of blindness work. During 1917 Commission Social Service nurses began working with local boards of education in providing sight-saving classes for groups of children with defective sight.

- 1920- A reorganization of the Commission for the Blind took place during 1920. Policies of the commission were reshaped; work of special sections was re-defined; work, which did not fit into the general scheme, was eliminated; and new branches were created. A special effort was made in this reorganization to obtain closer cooperation with local agencies for the blind throughout the state, and attempts were made to organize associations for the blind in communities where none existed. During the summer of 1920 the Commission for the Blind

conducted its first sale of articles made by blind persons in New York State at the Watermill Shop on Long Island.

- 1922- The New York State Blind Relief Act was enacted. Local communities under the supervision of the Commission gave direct financial assistance to blind persons for the Blind, which was responsible for investigating need.

- 1927- Plans were completed on July 1, 1927 whereby the New York State Commission for the Blind was made a bureau of the State Department of Charities.

- 1928- On July 1, 1928 a social department for the prevention of blindness was created by the Commission for the Blind. With the assistance of the Medical and Advisory Committee, a general program was initiated with emphasis on educational work, assistance to professional groups, and cooperation with State departments and local organizations.

- 1930- The Commission took a census of the blind persons in New York State. As of June 30,1930, there were a total of 8,875 blind persons in the state. Of these 4,580 were New York City residents, and 4,295 resided in areas of the State outside of New York City.

- 1933- The Bureau (Commission) was made a Division of the Department (renamed the Department of Social Welfare in 1929) and the Executive Secretary became an Assistant Commissioner of the Department.
    - Professional services for preschool blind children were inaugurated by the Division for the blind with the temporary employment of a preschool educator.
    - The Division for the Blind began sponsoring a "Survey on Eye Conditions" course at the School of General Education, New York University. Later, this course was transferred to Columbia University where it was co-sponsored by the New York Institute for the Education of the Blind. The course became a required subject for teachers of the blind.

- 1935- As part of the WPA project, the United States Library of Congress manufactured several hundred Talking Book Machines for loan to blind persons throughout the country. From the initial agreement of the Division for the Blind, to be responsible for the quota allocated to New York State has grown the present-day Commission for the Blind Talking Book Machine program.

- 1937- The State Department of Social Welfare Division for the Blind was renamed "Bureau of Service for the Blind" and the chief executives title was changed from Assistant Commissioner to Director. Various activities of the bureau at the time were prevention of blindness, home teaching, finding employment for the blind persons, industrial employment in homes, stimulation of

voluntary agency workshop programs through the loan of equipment and giving of instruction, sales of article made by the blind, and investigation of applications for relief under the provisions of the Relief Act of 1922.

- 1938- The Federal Social Security Act was enacted during this year. Aid to the Blind (AB) and other public assistance programs were established in New York State as locally administered public welfare programs supervised by the State Department of Social Welfare.

- 1941- The New York State Social Welfare Law was amended to provide that the Commission for the Blind would continue to exert and perform its duties subject to the supervision and control of the State Board of Social Welfare. It continued as a bureau of the Department of Social Welfare.

- 1944- The Commission for the Blind vocational rehabilitation program was established as a Federal State program with its headquarters in Albany.

- 1945- The name of the State Department of Social Welfare Bureau of Services to the Blind was changed back to the Commission for the Blind of the New York State Department of Social Welfare. Mandatory Reporting of blindness became law, and a legal definition of blindness was formalized in New York State. This definition is: "A blind person shall be defined as one who is totally blind or has impaired vision of not more than twenty/two hundred visual acuity in the better eye and for whom a diagnosis and medical finding show that vision cannot be improved to better than twenty /two hundred; or who has loss of vision due wholly or in part to impairment of field vision or to other factors which affect the usefulness of vision to a like degree."

- 1954- A study of the Commission for the Blind's organizational structure and of each of its major program activities was initiated.
  Amendments to the Federal Randolph-Sheppard Act (Public Law 565) tied the Concession Stand program more closely to the Vocational Rehabilitation program with emphasis on the small business enterprise aspect of the program.

- 1955- The Commission for the Blind was reorganized into three major program sections. The professional and Technical Services section included programs of Eye Health, Services for Blind Children, and Community Services. The Business Services section included programs related to Vending Stands, Production and Marketing, Office Management, and Accounting. The Vocational Rehabilitation Service constituted the third major section.

- 1956-60- A review of Commission for the Blind programs during this period resulted in a clarification of Commission policies and goals with primary emphasis being placed on the following: expansion of the interpretative, educational and standards setting roles of the Commission in the field of work for the blind; development and strengthening of local voluntary agency services for

the blind; advisory and consultative role of the Commission; the coordination of the program of the Commission within the Department of Social Welfare and with other related State and national agencies; the advisory role of the Board of the Commission for the Blind; the elimination of segregation and preferential treatment unrelated to needs caused by blindness, the substitution of skilled professional services for those based on an emotional or "pity" approach to blindness; and the integration of blind persons into the normal activities and services of the community.

- 1961- As a result of an extensive survey of positions within the Commission for the Blind by the Civil Service Department Classification Division, minimum qualifications and salaries were raised for many professional positions unique to the Commission for the blind, in line with the Commission for the Blind shift in program emphasis.

- 1962- Oscar Friedenshon was promoted to the position of Director of the Commission for the Blind. Mr. Friedenshon is the first man to hold this position in the history of the Commission.
    - The Telephone Pioneers, a voluntary organization of long-term Telephone Company Employees, agreed to repair Talking Book Machines without charge and are doing so in five major Upstate cities and in New York City.
    - The entire Register of the Blind was made available to the Department of Motor Vehicles for their action in arranging for up-to-date eye examinations for legally blind persons, who have retained their Motor Vehicle Operators Licensees in New York State. This process will be an ongoing one with all newly registered blind persons.
    - An institute relating to leadership in program planning was held at Arden House for administrators of all the agencies for the blind in New York State. A new major office of the Vocational Rehabilitation Service, located in Jamaica, was opened to serve Suffolk, Nassau and part of Queens. * As a result of a change in programming the rest of the missions most dire sales, the 78 Chambers Street Shop, was terminated. This change in focus has resulted in more extensive consultative and advisory production and marketing aid to workshops for the blind.

- 1963- The Commission for the Blind assisted in writing legislation, which clarifies the sale of blind-made products. The bills have passed the legislature. The Commission also participated in legislation, which mandates regular eye examinations for obtaining motor vehicle licenses. This legislation has also been enacted into law. The first training unit in an agency for the blind was created for students from three New York City colleges. These students are studying for a master’s degree in Guidance and Rehabilitation Counseling. The Commission has undertaken a program of distribution of free radios to blind persons on public

assistance. This distribution is being done for the American Foundation of the Blind.

2013- CBVH changes its name to NYS Commission for the Blind and celebrates its 100th anniversary.

Compiled by Michael Godino, Lisa Senior, Diane S.Weiss, Nancy D. Miller and the members of the NYC Youth and Vision Loss Coalition.
First Edition December 2014

8. 2. Cortical Visual Impairment Resources

Cortical Visual Impairment: Parent Resources
VISIONS Services for the Blind: Vision Center on Blindness

The Visual and Behavioral Characteristics that Typically Accompany CVI

Color preference: Present materials that are made of the student's reported preferred color and then compare the response to behavior when objects of a nonpreferred color are presented.

Need for movement: Present single objects of the preferred color on a stable surface and compare the student's visual response to the response when the same object is moving in space. If the student displays little or no visual attention to the moving object (that is, does not quiet, open his or her eyes, turn in the direction of the target, or make eye-to-object contact), present an object that has shiny or reflective surfaces, such as a Mylar pom-pom or pinwheel.

Visual latency: When presenting both known and novel objects, note the amount of time it takes for the student to notice the presence of the object. Also note when the latency, or slowness to respond, occurs in the session and what conditions or materials are associated with latency.

Visual field preferences: Note preferred visual fields throughout the session. Present a moving object in the right, left, upper, and lower peripheral fields. Note, too, whether the student turns or positions his or her head to align the right or left eye in order to identify or examine the details of the object.

Difficulties with visual complexity: Present objects of a single color (using the student's preferred color when one is reported), then objects that have two colors, and then three colors, and, finally, highly patterned objects.

Light-gazing and nonpurposeful gaze: Position the student near primary sources of natural and artificial light. Compare potential light-gazing behavior under conditions of high illumination with conditions of indirect or subdued lighting. In some cases, students will require low lighting during the assessment to be able to give visual attention.

Difficulty with distance viewing: Place an object that is familiar to the student on a single-color background. If the student can visually locate or fixate on the target, increase the complexity of the background and decrease the size of the target object.

Atypical visual reflexes: Attempt to elicit the visual blink and visual threat reflexes several times in a row—perhaps two or three times—and several times during the assessment session. Be aware of the possibility of habituation; that is, the student's blink responses may lessen if the evaluator repeats the touch or threat too many times in a row.

Difficulty with visual novelty: Present some objects that are familiar and some that are novel. Use visually simple objects for this task.

Absence of visually guided reach: If the student can reach away from his or her body, place a familiar and then a less familiar object on a simple background and observe the type of looking and reaching pattern used by the student. Repeat this activity with the target object presented on a more complex background.

Cortical Visual Impairment: Parent Resources
VISIONS Services for the Blind: Vision Center on Blindness

Background Information

Cortical visual impairment (CVI), also referred to as cerebral visual impairment, is a term used to describe visual impairment that occurs because of brain damage (Huo et al., 1999). CVI differs from ocular forms of visual impairment in that the interference in visual function exists not in the structures of the eye or optic nerve, but in the visual processing centers and visual pathways of the brain (Jan & Groenveld, 1993). CVI is a term that may be used to describe a condition when a child or adult is visually unresponsive but has a normal eye examination or an eye exam that cannot explain the individual's significant lack of visual function; he or she may have an abnormal MRI (magnetic resonance imaging) or CAT (computed axial tomography) scan that shows damage to parts of the brain such as the visual cortex or optic radiations.

It is important to recognize that experts do not agree whether cortical visual impairment, cerebral visual impairment, neurological visual impairment, brain damage–related visual impairment, or some other term will ultimately be chosen as the most appropriate description of visual dysfunction stemming from damage to the visual centers of the brain. According to Gordon N. Dutton (personal communication, May 10, 2006) and James Jan (personal communication, May 11, 2006), at this time, the term cortical visual impairment is more commonly used in North America, while cerebral visual impairment is generally used in Europe. There is currently a lack of consensus about the conditions and causes encompassed by these terms.

Critical Period in Visual Development

For Hubel and Wiesel (1970), the period of plasticity for visual development is most pronounced in infancy, and in human infants the brain is believed to be most plastic between birth and age 3 years. Studies by Norcia and Tyler (1985) and Orel-Bixler (1989) describe the critical phases for the development of acute vision as occurring in an early period from birth to 10 months of age and a later period of slower development from 10 months to nearly 10 years. According to Atkinson (1984), however, human visual development is largely complete by 6 months of age. Although consensus regarding the specific time frame surrounding the period of plasticity does not yet exist, many theorists agree that the greatest opportunity for vision development occurs early in life and that there is a finite amount of time available to expose children to appropriate visual inputs that will stimulate the development of visual functioning in an optimal way.

Based on these findings, it is important to recognize that, to improve their visual functioning, children who sustain serious brain injury in infancy or early childhood may be able to "tap into" the critical period of visual plasticity when visual function is being developed. This period provides a window of opportunity for neuronal activity responsible for vision to be routed from the damaged areas of the visual pathways and primary visual cortex to other areas of the brain responsible for visual functions (Tychsen, 2001). Even if the window of plasticity for visual development remains open for as long as 10 years of age, the most opportune time for meaningful stimulation in all likelihood occurs in early infancy. For this reason, infants with brain injury should be screened as early as possible for potential vision difficulties associated with CVI.

Importance of EI

All too often, parents report that when eye care or medical professionals examine their infant who demonstrates atypical "seeing" behaviors, they are advised that the child's eyes are normal. Many families report being given comments such as: "Children with brain injuries sometimes act this way," "There is no treatment for your child's vision," "The eyes are fine, we just don't know how well he understands what he sees," "She is blind and there is nothing that can be done," and "There's no harm in waiting, sometimes children grow out of this vision delay." Remarks like these reflect the confusion surrounding CVI. And there are, in fact, understandable reasons for this confusion. The eyes of children with CVI frequently appear to function normally. In children who have CVI, the

visual systems of the brain do not consistently understand or interpret what the eye sees, and, depending on the extent and severity of damage to the brain, visual function can be affected in a wide variety of ways. Many ophthalmologists and other medical practitioners concerned with the measurement of visual acuity may not identify the presence of CVI in a child whose eyes are normal or who has an ocular condition that does not explain the profound loss of visual function. Many early interventionists may not regard a child with a normal ocular system as eligible for vision-related services.

Incidence of CVI

As already indicated, in the past 20 years debate has occurred among medical professionals about the nature of CVI. Educators of students with visual impairments also have discussed the appropriateness and efficacy of providing specialized instruction to children whose visual differences arise in the visual pathways and processing centers of the brain, rather than in the ocular structures of the eye. CVI may not always be viewed in every quarter as a "legitimate" form of visual impairment, particularly by some eye care specialists who document normal eye examinations in children with CVI, and by some vision educators whose training primarily centered on the needs of children with ocular visual impairments. Despite these questions, however, CVI is recognized today as the primary cause of visual impairment in children in so-called first world countries in which advanced medical interventions are available to infants and children (Skoczenski & Good, 2004), and it is likely to remain so for the foreseeable future.

Children who once died as a result of prematurity or brain injury are now surviving in greater numbers. In 1963, Patrick Bouvier Kennedy, newborn son of John and Jacqueline Kennedy, died from complications of prematurity. President Kennedy's son was born at 34 to 35 weeks' gestation, and infants of that gestational age now survive at rates greater than 95 percent in the United States. According to Als (1999) more than 95 percent of infants born 8 to 12 weeks premature will survive if cared for in a neonatal intensive-care unit. Neonatologists, pediatric neurologists, and other pediatric practitioners who specialize in caring for infants or children with brain injury have made significant advances in the survivability of critically ill and premature children. Many more children now survive, but the total number of children with significant disabilities has also increased. Decreased mortality has not resulted in decreased morbidity. Younger and more fragile infants and children have a greater risk of neurodevelopmental impairment. There is an important relationship between advances in medicine and numbers of neurologically affected surviving individuals, a relationship resulting in greater numbers of infants and children with CVI. As Dutton has observed, "It is estimated that over 40 percent of the brain is devoted to visual function, so it is not surprising that a large proportion of children with damage to the brain have visual problems" (2006, p. 4).

Southern California CVI Consortium

CVI Packet

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Cortical Vision Impairment: Overview

Bill Takeshita, O.D., F.A.A.O., F.C.O.V.D.

What is cortical vision impairment?

Cortical vision impairment (CVI) is one of the leading causes of vision impairment among children in the United States. CVI is a condition in which the visual pathway and visual processing centers of the brain are damaged and result in reduced vision. Children and adults of all ethnicities may have cortical vision impairment.

Are children with CVI totally blind?

No. Most children with CVI have vision, but the manner that they use their vision is different. Children with CVI generally have reduced central vision, and this can affect their ability to see small details, distant objects. It also affects their ability to make eye contact with people. Children with CVI often turn their eyes such that they use their peripheral or side vision to look at objects. For example, they often turn their head away from the objects they reach for. As a result, it often appears as though they are not looking at the object of interest.

Children with CVI also have other very unique visual behaviors. They frequently are very interested in looking at objects of a particular color, such as red. These children will look at red clothing, red apples, or a red Elmo toy, but they may not look at other colored objects. They often enjoy staring at lights, rotating and moving objects, shiny patterns, or high contrast toys. They may prefer to look at rotating ceiling fans or the credits at the end of a video, but they will not look at the movie.

Is there a cure for CVI?

There is no medication or surgery that will correct the vision impairment of children with CVI. However, a recent paper published in 2012 by Roman, et. al. reported that 95-percent of children with CVI developed higher levels of vision within a period of 3.7 years after receiving a program of visual intervention. In their research study, they decorated the work areas that the children played in and performed specific activities that involved the use of lights, colors, contrast, and other patterns.

What causes CVI?

The most common cause of CVI among newborn infants is the reduced level of oxygen to the brain. Anoxia, hypoxia, respiratory distress, asphyxia, and brain hemorrhage all affect the amount of oxygen that reaches the visual centers of the brain. Other factors that are associated with CVI include intraventricular hemorrhage, periventricular leucomalacia, hydrocephalus, meningitis, seizure disorder and trauma.

Does CVI affect motor and language skills?

Children and adults with CVI may have other concurrent problems in addition to vision impairment. When a person experiences the lack of oxygen, infection, or trauma to the brain, it is possible that numerous functions are affected. Motor skills, speech, language, learning, and other skills may be involved if the brain injury has affected the regions of the brain that control these functions. It is very important that all children with CVI receive complete evaluations to determine if occupational, physical, speech, and other therapies are required.

What can I do to help my child to use his or her vision?

The first thing parents and care givers should do is to have their children evaluated by a team of professionals. Ophthalmologists are required to examine the structures of the eyes and brain to determine if any medical procedures are required. Next, a functional low vision examination by a pediatric low vision doctor is recommended to determine the visual strengths and weaknesses of the children and then to develop a visual intervention treatment program. Third, a teacher for the visually impaired, occupational therapist trained in low vision, or an early intervention specialist will help the parents to implement the treatment program.

Enhancing Your Home for Your Child with CVI

The appearance of your home can affect the manner that your child uses his or her vision. Drs. Hubel and Weisel won a Nobel Prize for their research in which they demonstrated that the environment that one is raised in affects the growth of the brain cells that are responsible for vision. In their research, they found that kittens that were raised without vision later developed vision by being exposed to a stimulating visual environment with colors, contrast, and lights. This important research showed that by enhancing your home with colors, lights, patterns, and toys, you may stimulate the use of your child's vision.

Modifying your home does not require a lot of money. You may already have many items at home you can use to create a visually stimulating environment for your child. Consider going to local stores and asking them for left over paint, carpet, and other materials that you can use. Home improvement stores, fabric stores, paint stores, and schools are often very generous in providing discontinued items, samples, or donated materials in order to create a visually stimulating environment for your child.

How Do I Increase the Brightness of My Home?

Vision requires adequate light to enable your child to see. Many apartments and homes are not well lit or have limited natural light.

- If you have drapes or vertical blinds, open these in order to allow more light into the home.
- Consider painting the walls an off-white color to brighten rooms that are dark. Some paint stores may be willing to donate left over paint.
- If you are not able to paint the walls of your home, create a section of the home that will be brighter. Supermarkets, schools, craft stores, etc. usually have white butcher paper or poster board that can be taped to the walls in the areas that your child plays to brighten the room.
- Paint colorful flowers or other shapes on the wall or on poster board/butcher paper using a primary color like red or blue to provide contrast.
- You may apply large stickers or pictures of Sesame Street, Blues Clues, or other characters on the wall. Tablecloths for birthday parties or colorful wrapping paper can also be used as bright and colorful decorations.
- At night, turn on a lamp that will illuminate the room.

How Do I Increase Colors and Contrast in My Home?

The use of colors and contrast are very important. Many children have a favorite color and it is very important to use that color as you make changes in your home. By using pillows, cups, plates, and toys that are your child's favorite color, your child will be more interested in using his/her vision.

- Use your child's favorite color to accent specific objects and toys in the room. For example, place a red picture of Elmo on the bedroom wall, place red pillows on the bed, and paint the trim on the crib, bed, or door jams in the bedroom red. Often children with CVI are most drawn to red, yellow, and purple but every child is different, so it is important to experiment and determine what color your child is most attracted to.
- When using your child's favorite color, make sure you use opposing colors to provide high contrast. For example, if your child loves yellow, place yellow pictures of Big Bird on a blue background rather than on a white background.
- Paint the light switch covers in your child's room his or her favorite color.
- Consider painting a 6-inch bold line across the walls or various areas of your child's room. This will help your child know his or her room.

- Place colorful pillows on the floor or sofa where your child plays. Use a color that your child prefers to look at.
- Use neon paint and paint geometric shapes on a poster board and place them on the walls where your child plays.
- Consider tying balloons filled with helium so that they float in the room. Children enjoy looking at the balloons, especially when they are the child's favorite color or are shiny.
- Create a mobile that has contrasting colors, such as red and yellow
- Use a blanket or a sheet of a solid color as a background to place your child's toys on. The solid background will make it easier for your child to locate toys. For example, use a black sheet or blanket with a red Elmo on it.
- Use colors and contrast when feeding your child. You can wrap a cloth that is your child's favorite color around his or her bottle. Use cups, utensils, and plates that are your child's favorite color and place foods of a contrasting color on the plate. For example, if your child loves the color red, use a red bowl and place cubes of apples in the dish.
- If you have stairs and steps at your home, place a strip of contrasting colored tape along the edge of the step so your child will see the steps.

How Do I Adapt Lighting Within My Home?

It is very helpful to have the proper lighting for your home. If your home does not have enough lighting, your child will not be able to see faces and toys. However, too much lighting can be very uncomfortable for your child. Ask your eye doctor about the specific type of lighting that would be most beneficial for your child.

- Desk lamps with a "cone shape" lamp shade are very helpful because all the light is directed on the toys your child is looking at. These desk lamps can be moved from the dining area to the play area very easily.
- Position the desk lamps such that your child cannot directly see the light bulb.
- If you are going to purchase a desk lamp, consider an Ott desk lamp because the bulb does not get hot; it produces a lot of light, and is easily moved from room to room. The cost is approximately $40.
- A torchiere floor lamp design is excellent in providing high levels of general lighting in a room. The lamp resembles a torch, where the light is projected upward onto the ceiling to provide illumination.

Toys That Encourage Children with CVI to Use Vision More Effectively

There are many items that you have at your home or may be purchase at low cost to use when playing with your child. Use items that are your child's favorite color and have properties that will increase your child's interest. The following are examples of toys and items that can be used when playing with your child to increase visual response to the environment. We've organized our list according to the unique visual and behavioral characteristics associated with CVI, referenced from Dr. Christine Roman's *CVI Range.*[1]

Caution: Please make certain that there are no small objects or parts that may injure your child or that your child may swallow. Your child's activities should be closely monitored at all times.

Color Preference

- Colorful Slinky
- Crinkly paper
- Sparkly kitten ball
- Pinwheels
- Metallic gift bags
- Bath mitts
- Mylar colored balloons
- Pom-pom
- Colorful measuring cup and measuring spoons
- Colored electrical tape
- Colored plastic utensils (forks, knives, and spoons)
- Colored plastic cups
- Place mats
- Cafeteria tray
- Penlights and flashlights
- Colored tooth brush
- Used golf balls, tennis balls, soccer balls, basket balls
- Velcro tape and elastic
- Poster board of various colors, including neon, black, and white
- Mardi Gras beads
- Gardening items such as colorful pots
- Mobiles for the garden
- Brightly colored cloth, fabric, and materials
- Spray paint
- Colorful bean bags
- Colorful pillows
- Colored Tupperware or plastic containers
- Colored scarf or snow cap
- Colored cellophane to make stained glass window
- Colorful food containers, cups, bowls, plates, and utensils.
- Colorful table cloths for birthday parties
- Wrapping paper

[1] Roman-Lantzy, Christine. Cortical Visual Impairment: An Approach to Assessment and Intervention. 2007. AFB Press, New York: 57-172.

Need for Movement

- Colorful Slinky
- Crinkly paper
- Sparkly kitten ball
- Pinwheels
- Pom-pom
- Large bouncy ball
- Soap bubbles
- Colorful measuring cup and measuring spoons
- Golf balls, tennis balls, soccer balls, basket balls
- Mobiles for the garden
- Mardi Gras beads
- Colorful bean bags

Objects with Reflective Properties

- Wrapping paper
- Colored cellophane to make stained glass window
- Pinwheels
- Metallic gift bags
- Metal bowls
- Baking sheets and muffin tins
- Metal whisk
- Blank CDs
- Mirrors
- Pom-pom

Light Gazing and Non-Purposeful Gaze

- Penlights and flashlights
- Lightbox
- Disco balls
- Decorative string of lights/Christmas lights

Difficulty with Distance Viewing

- Mobiles for the garden
- Soap bubbles
- Penlights and flashlights
- Colored cellophane to make stained glass window
- APH Invisaboard or a black presentation board to eliminate background clutter
- Large sheet in a solid color to use as a back drop to eliminate visual clutter in order to focus on a specific object or person at distance

Additional Toys for Children with CVI

1. **Fabric books**: one image per page, simple graphics, bright colors, crinkle paper
    a. **Giant Soft Book**: cloth book~large (10" square), one image per page, multiple bright colors, textures, peek-a- boo flaps, squeaker and mirror - $22.59
    b. **Find the Ball**: cloth book~medium (7" square), one image per page, bright colors, crinkle paper, attaching loop - $16.99
    c. **Jungle**: cloth book~small (4" square), one image per page, simple graphics, bright colors, crinkle paper, links for attaching - $9.99
2. **See & Say/board book**: one image per page, high contrast, simple graphics - $9.99
3. **Buddy dog**: high contrast, vibration, texture - $32.99
4. **Bizi ball**: one piece pull apart ball, high contrast, crinkly ribs - $25.99
5. **Mini rib-it-ball**: high contrast, easy to grasp, crinkly ribs, vibration - $24.99
6. **Car seat gallery**: simple graphics, high contrast - $16.99
7. **Double feature mirror**: 10" x 14", mirror on one side, high contrast patterns on one side, ribbon ties for attaching - $32.99
8. **Gripper rattle**: bright red and yellow - $10.99
9. **Roly poly chiming clown**: weighted chime toy with red body, high contrast face - $24.49
10. **Ambi lock a block**: shape sorter, high contrast primary colors, raised rims - $19.99
11. **Baby driver**: bright red and yellow steering wheel, suction cup base - $22.99
12. **Rainbow peg play set**: yellow peg board with bright pegs - $19.99
13. **Spinning melody top**: bright color, top lights up and plays melody when spinning - $4.49
14. **Non-stop light show/purple**: spinning table top light show - $15.99
15. **Meteor storm/spectra spinner**: ten sets of lights spin, changing color inside clear globe - $8.49
16. **Light show creator**: multicolored light patterns, soft whirring sound, cooling breeze, handheld or placed on flat surface - $15.99
17. **2-headed light show**: handheld light show, 32 magical lighting effects - $19.99

These toys can be found at:
Playopolis Toys
www.PlayopolisToys.com
Christina Wallerstein, Founder and Chief Play Officer
Voice: 877-579-9300 (no charge)
Local: 626-792-2380 (local)
Fax: 626-585-8675

This list was compiled by the Family Resource Project at the Center for the Partially Sighted along with Early Interventionists and Teachers of the Visually Impaired

Considerations and Recommendations for Play Activities

Simple play with your child is perhaps the best way to encourage your child's development. In addition, play also promotes the development of your child's muscle control, balance, speech, social skills, vision, and the list goes on and on. Interactive activities such as playing peek-a-boo, taking turns picking up Cheerios, reaching for a flashlight, or putting objects in and out of containers all have positive effects on your child's overall development and may encourage visual learning, as well.

In the Phase I, II, and III play activities listed below, you should be mindful of positioning, talking to your child, and allowing your child the time to see. After setting up an activity, try to keep your attention on observing, waiting, and allowing your child the time to respond.

Positioning: Always, remember, that positioning and re-positioning play an important factor in a child's response to their environment. Positioning can impact latency, fatigue, and overall endurance for an activity. If your child is not responding or responding well, look at their positioning and the position of objects and decide if movement is necessary. Sometimes, a slight change in the positioning of a chair or moving an object to the right or left can have a dramatic impact on a child's visual response.

Talk to Your Child: Talk to your child to capture his or her attention but then keep quiet for a period of a minimum of 15-seconds to allow your child to concentrate on looking at your face. Interactive activities stimulate the development of the brain and may help your child learn to maximize vision.

Giving Your Child the Time to See: Present a toy and wait. Do not talk or provide auditory input after asking your child to look. Keep the object in the same visual field long enough for your child to see it. Use a solid contrasting background if that helps him/her find the object.

Phase I Play Activities

During Phase I play, the goal is to assess your home and provide your child with everyday items that are visually interesting to look at. Ask your eye doctor what features are most interesting for your child to see. For example, what color objects and toys are most visually engaging, what distance is best, which field of vision to use, how much time to allow your child to visually attend, should toys be moving or stationary, and what level of lighting should be used.

In order to best understand how your child's visual diagnosis can impact your child's development, it is best to discuss your child's condition with the Pediatric Ophthalmologist or Developmental Optometrist. The following play activities are not meant to be a treatment plan but are simply ways to encourage your child's interest in using his or her residual vision in play.

1. **Enhancing the Environment**: Adapting your home and the areas where your child plays to make it more visually stimulating. For suggestions, please refer to the section on "Enhancing Your Home for Your Child with CVI."
2. **Prepare a Play Area**: Select an area that is free of clutter, noise, and other distractions. Position your child such that your child is comfortable. Your child should have windows or doors at their back (they should not directly face windows or doors). Position a desk lamp behind your child and turn off the over-head lights so that your child will not stare at the ceiling light. Place a black, gray, or contrasting solid color sheet or blanket to place the toys on to make it easier for your child to see.
3. **Favorite Color**: Use your child's favorite color to stimulate looking. For example, if your child loves the color yellow, use yellow rubber duckies or Big Bird toys. If your child prefers the color red, use Elmo and other red toys. Use blankets and pillows that are your child's favorite color and place them on his or her bed.
4. **Proper Distance**: Present toys, your face, and other objects at the distance and location that the doctor recommends. Most children will be able to see objects better when they are within arm's reach.
5. **Shake and Move**: Move the toys and objects occasionally to stimulate interest. Most children will become more interested if you periodically move the toy or object.
6. **Wake Up Time**: When you wake your child up in the morning, position your face at the distance that your child is able to see best. Turn on the room lights or open the drapes. Move your head from side to side as you talk to your child. If your child has a favorite color, wear a snow cap that color or wear a scarf to get your child's attention. Colored head bands and wrist bands are also helpful to wear to get your child's attention. Use a piece of black poster board to put behind you if your child has difficulty looking at your face because of distractions in the background.
7. **Dress Time**: When you begin to dress your child, move the clothing and allow your child to follow the clothes with his or her eyes. Try to use clothes that are your child's favorite color and move it from one location to another. Encourage your child to reach and touch the clothing. Shake the clothing and allow your child plenty of time to visually locate the clothing. Some children may need as much as 15-seconds to process the information.
8. **Wash Up**: The bathroom is another great place to stimulate vision. Take your child to the bathroom and allow your child to turn on the lights. Use a colored switch plate (you can spray paint it yourself) so your child can see where the light switch is located. Allow your child to turn the lights on and off. Wash your child's face with a face towel that is your child's favorite color. Play peek-a-boo with the wash cloth.
9. **Mirror Play**: Use a hand mirror and place it in front of your child. Observe your child as he or she looks at his or her reflection. Move the mirror slowly to develop eye movement skills.

10. **Time to Eat**: During meals, use the same principles to stimulate vision. Wrap a colorful cloth that is your child's favorite color around the bottle and allow your child to follow the bottle before he or she gets to drink from it. Similarly, use cups, plates, and utensils that are your child's favorite color. Use contrasting colors to make it easier to see food. For example, use a red place mat, a white plate, and then place strawberries on the plate.
11. **Let's Do the Dishes**: Depending on your child's age, you may allow your child to help when doing the dishes. Use colorful dishes and allow your child to wash, rinse and dry the dishes.
12. **Stained Glass Window**: Create a stained glass window by affixing colored cellophane paper on the window. Encourage your child to look at the stained glass/cellophane, crawl towards it, reach for it, etc.
13. **Spinning Drum**: Make a high contrast, spinning drum by using a Quaker Oats container or a 2-liter soda bottle. Wrap a white piece of paper around it and then use colored electrical tape to form bold stripes on the paper. Spin the drum slowly to engage your child's attention and allow your child to follow the drum.
14. **Toy Bar**: Create a toy bar that can be positioned over your child so that your child can look at toys in a comfortable position. Use elastic straps and affix rubber ducks, Slinkys, colorful balls or bells, or other toys on the bar. You can also make a mobile with suspended CDs (CD's are shiny and reflective).
15. **Video Time**: Use visually stimulating videos such as Baby Mozart and Baby Einstein when you are busy performing other activities. Screen Savers on the computer are also visually stimulating.
16. **Pom-Pom Play**: Use shiny pom-poms and shake them to attract your child's attention. Move the pom-poms in different directions and encourage your child to follow it.
17. **Spinning Pinwheels**: Use colorful spinning pinwheels and position the pinwheel at the proper distance. Allow your child to look at the pinwheel. Occasionally, move the pinwheel and encourage your child to follow the pinwheel as you move it.
18. **Ceiling Fans**: Many children enjoy looking at moving objects. You can position your child under a ceiling fan. Tape a strip of colorful reflective material like Mylar on each blade of the fan and allow your child to look at the fan.
19. **Glove and Mitten**: Use colorful gloves that have one side of the glove one color and the other side a different color. Simply move your hand to allow your child to see the change in color of your hand. Put the gloves on your child's hands and encourage visual attention to their hands as well.
20. **Magical Mylar**: Mylar is reflective and bright so it attracts visual attention for a variety of reasons. Use colored Mylar wrapping paper or an old deflated Mylar balloon and cut it in strips. Glue these strips on furniture or other objects near your child or in their play area. Use a fan to blow on the strips, so they move and catch light.
21. **Lighted Pop Beads**: Use a penlight inside a pop bead that is the child's favorite color. As the pop bead becomes a familiar object, you can use the pop bead without the light and add more pop beads or introduce another color.
22. **Familiar is Best**: Place toys and objects that your child is familiar with in the areas that your child plays or spends most of the day. You do NOT need to have a large number of toys. It is better to use the toys that your child is most familiar with.
23. **Light Box Activities**: Your school or early intervention teacher may recommend activities using the Light Box. The Light Box provides more illumination and contrast to encourage your child to look. Place colorful plastic beads in a Zip-Lock bag and place it on the Light Box. Similarly, you may use food coloring and hair gel in a plastic Zip Lock bag and place it on the Light Box.

Phase II Play Activities

During the second stage of play, we recommend activities that will encourage your child to use vision, hearing, touch, taste, and smell to learn about cause and effect. In Phase I, children are building visual behavior; in Phase II, vision in play stimulates motivation and action.

1. **Daily Routines**: Continue to perform the daily routine of activities when you awaken, groom, dress, and feed your child.
2. **Use Multiple Colors**. Present toys that include a combination of two colors with one color being your child's favorite color. Checker board towels and patterns are helpful. Use two colors to mark and paint the door jam or door knob in your child's room or specific play areas.
3. **Textures:** Use pillows and materials of various textures so your child will be able to feel and begin to notice differences in textures.
4. **Crinkly Paper**: Use colored paper that is crinkly. Encourage your child to reach and grab the paper. Children enjoy the sound of this paper. Encourage them to look for the paper and then grab it with their hands.
5. **Hand Exploration:** Babies and children like to watch their own hand movements. Put mittens on your child in their favorite/preferred color. Allow them time to observe their hands in the mittens. To encourage them to look at their hands, play pat-a-cake or games like head, shoulders knees and toes while you guide their hands to touch different body parts. Socks in their preferred color can encourage them to look at their feet.
6. **Bath Mitt Play:** Use bath mitts when giving your child a bath to stimulate vision. Move your hands and encourage your child to reach for your colorful bath mitt.
7. **Colored Soap Foam:** Write on the bathroom wall with colorful soap foam and allow your child to touch the colorful foam with his or her hands.
8. **Toy Bar Play:** Make a toy bar out of PVC and hang soda cans, bottles. You can also use CD's and paper plates decorated with black markers. Affix the items using Velcro tape. Encourage your child to reach and grab the toys or soda bottles and remove it.
9. **Grab the Golf Balls**: Affix one side of a Velcro trip to golf balls or small whiffle balls and the matching strip on a cookie sheet or wooden board. Encourage your child to remove the golf or whiffle balls from the sheet/board and place them in a coffee can or container.
10. **Coffee Can Play:** Ask your child to put objects into coffee cans. Encourage your child to cross the midline of his or her body. For example, place the coffee can on his or her left side and ask them or assist them to use their right hand to cross midline and insert the balls in the can.
11. **Fisher Price Crib Toy Aquarium**: This is a toy that can be attached to the crib to encourage reaching.
12. **Giant Peg Board**: Create an activity board. This is a pegboard with various objects connected with zip ties and shower curtain rings. Your child can reach for the objects with guidance from the board. Because the toys are attached, it is easier to find them and if they lose visual contact or their grasp on the toy, they can still find the object attached to the board.
13. **Cookie Sheet Play.** Use a cookie sheet with Velcro strips. You may place various toys on the cookie sheet by using Velcro. Place the toys on the cookie sheet and encourage your child to reach and grab the toys.
14. **Felt Board**: You can use a piece of black felt and attach it to a poster board or a large piece of cardboard. Cut geometric shapes of your child's favorite color from felt and attach the shapes on the felt board. Encourage your child to pull the shapes off the board and later put them back on the board.
15. **Activities in the Car**: Place a colorful cloth or blanket on the back of the car seat in front of your child so that your child has something interesting to look at. Consider suspending a colorful Slinky or

create a colorful mobile and allow it to hang in front of your child in the car. Do not use toys that have bells attached or that make noise.

16. **Cause and Effect Toys**: Use toys that have cause and effect such that when a button it pressed, an object such as Big Bird or Elmo pops up.
17. **Time to Get Dressed:** When purchasing clothing for your child, purchase clothes that include your child's favorite color but also has another color on it. For example, rather than just purchasing a red t-shirt, buy a t-shirt that has red and yellow stripes.
18. **Feeding Time**: Continue to use colorful utensils, plates, napkins, and cups that include your child's favorite color. However, encourage your child to reach for the cups and food items so that he/she learns that something beneficial comes from reaching and grabbing food.
19. **Bath Time**: Use yellow ducks or other plastic toys that can float and place them in the water with your child. Encourage your child to follow the toys and reach for them.
20. **Music Time**: Spend time playing with musical instruments such as maracas, shakers, drums, bells, play pianos, rhythm sticks, etc. and paint them bright colors or apply colorful tape. Allow your child to experience cause and effect playing the instruments.
21. **Tap the Switch:** Use colorful switches and connect them to a tape recorder or CD player. Teach your child that he or she can turn the music on and off by tapping the switch.
22. **Crawling and Walking Guide**: Paint a bold stripe approximately 4-inches wide in your child's favorite color along the wall to give your child something to follow when he or she walks or crawls.
23. **Little Room**: You can create a small room for your child using cardboard or a small tent. Suspend visually stimulating toys from the ceiling and allow your child to lie under the objects and reach for them. Ask your teacher for children with visual impairments to assist you with this project.
24. **Toy Bin**: Make a box decorated with your child's favorite colors and place his or her favorite toys in the box. This will teach your child what to look for and where to find the toys that he/she wants to play with.
25. **Let's Go for a Walk:** Take your child for a daily walk and show your child interesting objects and things in the neighborhood. Your child may be interested in looking at the mail box, a rose, fire hydrant, and other objects. Allow your child to touch and smell these objects.
26. **Let's Go Shopping:** Take your child to the grocery store and allow your child to explore fruits, vegetables, and other items in the market.

Phase III Play Activities

During this phase, the goal is to expand your child's ability to use his or her vision in order to solve problems for daily activities. It is also a time to encourage your child to look at new toys, objects, and items at further distances. Continue to use the activities described in Phase I and Phase II when you awaken, dress, groom, and feed your child.

1. **Facial Expressions and Body Language**: Use facial expressions and body language to provide additional cues to your child about what you are trying to communicate.
2. **Looking Further**: Increase the distance from which you bring items to your child. For example, you may bring a container of orange juice from the refrigerator and ask your child if he or she would like it. Try to have him or her make visual contact with it in order to encourage your child to look further.
3. **Back Up**: Move further from your child to teach your child how to keep his or her eyes on you as you move further away. Similarly, move food items, clothing, and toys further back so that your child will learn to focus at further distances.
4. **Your Choice!:** Allow your child to have a say in which clothing he or she wants to wear by allowing your child to select from two different clothing items. Similarly, use two separate drink containers and encourage your child to reach for the container of what he or she wants to drink. Choice making builds autonomy and self-esteem, while also incorporating visual learning.
5. **Crowded Background**: Begin to include other objects in your child's play area so that your child will learn to focus on the object of interest even when there are other distractions. For example, when feeding your child strawberries in a bowl, consider adding bananas as well.
6. **Increasing Complexity:** Present toys and other objects to your child on a patterned background. This will teach your child how to find the object of interest on the cluttered background. For example, present toys on a patterned blanket rather than a white or blank one.
7. **I Spy…:** Use the "I Spy" books and ask your child to find a specific item that is hidden within the other items. You can also perform this by gathering various household items and placing them on a cafeteria tray or large Tupperware lid. Ask your child to find the specific item on the cluttered tray.
8. **Audio Distractions**: Incorporate sounds and other distractions to observe if your child can still keep visual attention on the target when there are sounds or music that may be distracting.
9. **Obstacle Course**: Create a small obstacle course in your home by placing pillows or other obstacles like toys or stuffed animals that your child will have to navigate around. Observe how well your child uses vision to guide his or her body to crawl or walk while navigating around the obstacles.
10. **Slinky Toss**: Toss a colorful Slinky a few inches away from your child and encourage him or her to reach for it.
11. **Ball Play**: Place your child in a sitting position and roll a soccer ball towards your child. Teach your child to push the ball back to you. Later, use smaller balls. This will develop your child's eye hand coordination.
12. **Shape Sorters**: Use wooden puzzle boards or shape sorters that require your child to insert a round circle into the round hole, etc. There are many different Shape Sorter toys available with various shapes.
13. **Superimposing Blocks**: Use various shaped blocks and ask your child to superimpose or stack blocks of the same shape. Parquetry blocks and Tangram blocks are good for this activity. There are also very large blocks made of foam that can be used for this task.
14. **Copy My Design**: Use the Parquetry blocks, Tangrams or other blocks and give your child a matching set of blocks that you have made. You can create a pattern with two or three blocks and ask your child to copy your design.
15. **Pointing Game**: Encourage your child to look at an object or person by pointing to it/them. This will develop a sense of direction, visual attention and distance vision.

16. **Field Trips**: Take your child to busy locations to search for objects, such as the mall, a park, or an educational toy store. Ask your child to find specific items that you see.
17. **Balloon Play**: Play tap or toss with a colorful balloon and teach your child to tap the balloon in the air or to catch the balloon.
18. **Hide and Seek**: Play the game "hide and seek" in the home and encourage your child to use his or her vision to search for you or other toys that you have hidden.
19. **Sequencing Games**: Encourage your child to learn to count by counting coins or poker chips that are aligned on a table.
20. **Giant Pegboard**: Teach your child to insert the pegs into the pegboard from left to right. Later, you can place a sequence of colored pegs in the top row of the pegboard and ask your child to replicate the pattern on the second row.
21. **Stringing Beads**: Use larger beads and show your child how to string beads onto a pipe cleaner. Then, you can create a sequence of beads on a pipe cleaner and ask your child to copy the sequence.
22. **Decorate cookies or cupcakes**: Make a simple pattern like x's and o's, a smiley face, star, etc. with colored icing on cupcakes. Allow your child to replicate the pattern you have made.
23. **Follow the Map**: Use colored sidewalk chalk and draw a line that you and your child can follow to reach the surprise location, where there may be toys or other rewards.
24. **Dominoes**: Use dominos and ask your child to create a long sequence of the dominos by matching the number of dots from one domino to the next.
25. **Connect Four:** Use this commercially available game to encourage your child to use vision and develop eye hand coordination skills.
26. **Visual Memory Games**: Get various household items and place them on a sheet, a cookie sheet, or a tray. Allow your child to see what is on the tray. Ask your child to close his eyes and then remove one of the items and ask your child what has been removed. Take turns to allow your child to remove an item.
27. **Cardboard Box Play**: Kids love to play in large boxes. You can create a tunnel by opening up both ends of the box and decorating the inside surfaces of the box with your child.
28. **Colored Popsicle Sticks:** Use colored popsicle sticks and make a design with two or three sticks.
29. **Copy the Popsicle Stick Pattern**: Use different colored popsicle sticks to build a square, triangle, or capital letters and ask your child to replicate your design. Once your child has mastered this skill, use colored sidewalk chalk and ask your child to draw what you have made with the colored Popsicle Sticks.
30. **Swinging Ball**: Suspend a plastic Whiffle Ball from the ceiling using a hanging plant hook and string. Allow your child to sit or stand approximately 4-feet from the ball and slowly swing the ball. Allow your child to follow the ball and catch the ball with his or her hands.

iPad Applications for Developing Vision

The Apple iPad is an outstanding device to stimulate vision. There are many applications (apps) that are very affordable and can be used to develop your child's eye-hand coordination, eye movement skills, and understanding of cause and effect. The following is a list of apps recommended for developing your child's vision.

Phase 1

1. **Awesome**: This app involves a black background with multi-colored circles that can be moved when swiped. $0.99
2. **Baby Visual Light**: This app combines a simple picture with music and is displayed in a slide show format. Free
3. **Bubbles**: This app involves using the fingers to draw bubbles and then popping the bubbles by tapping them. $0.99
4. **Fluidity**: This app involves using an interactive fluid dynamics simulation, where fingers can be used to change the fluid display. Free
5. **iLoveFireworks**: With this app, your child can create a colorful fireworks display by tapping on the screen. $0.99
6. **Infant Zoo**: This is a visual stimulation game where a brightly colored screen and simple shapes transform into animal drawings. $2.99
7. **KaleidoBalls**: This app creates a kaleidoscope pattern just by touching the screen. Free
8. **Ooze**: Push and pull on interactive color-shifting goo to form mesmerizing patterns. Free
9. **Sensory Light Box:** This interactive light box has 21 different stimulating designs. $2.99

Phase 2

1. **Baby Finger**: Parents can touch the screen and cause action to begin. $0.99
2. **Fun Stars and Draw with Stars!**: Both apps involve using the fingers to draw streams of stars. In Fun Stars, the stars become fireworks when touched a second time. Free
3. **My Talking Picture Board**: This app allows you to use your own pictures from your photo library to use for visual discrimination. $19.99
4. **Talking Carl and Gugl**: This game involves an interactive green round and a red square characters named Carl and Gugl, who respond to various gestures and voices. $0.99
5. **Tap N See Now**: In this app, animals float on a screen, and with a light tap the animals move towards the viewer. Free.

Phase 3

1. **Go Away Big Green Monster:** This app involves an interactive story with a dark background. It allows the child to piece together parts of the Monster's face on the screen, including the eyes, hair, ears, and nose. $1.99
2. **Peek-A-Boo Barn**: This app has a red barn that moves until touched, causing the barn door to open and an animal to come into view. The animal then makes a sound and a voice says the name of the animal. $1.99

References

- Dutton, G. N. (1998). Visual problems in children with brain damage. http://www.rcophth.ac.uk/publications/focus5.html
- Good, W.V., Jan, J.E., Burden, S.K., Skoczenski, A., & Candy, R. (2001). Recent advances in cortical visual impairment. Developmental Medicine & Child Neurology, 43, 56-60.
- Good, W.; Jan, J.E.; Luis, D. (1994). Cortical Visual Impairment in Children. Surveys of Ophthalmology, 38:4, 351-364.
- Greeley, J. (1997, April). Strategies for working with cortical visual impairment. Presented at the Anchor Center for Blind Children Pediatric Interest Group, Denver, CO.
- Groenveld, M. (2003). Children with cortical visual impairment. http://www.aph.org/cvi/articles/groenveld_1.html
- Groenveld, M., Jan, J., & Leader, P. (1990). Observations on the habilitation of children with cortical visual impairment. Journal of visual impairment and blindness (JVIB), 84, 11-15.
- Harrell, L. (1992). Cortical visual impairment - a challenging diagnosis. Children's Vision Concerns: Looks beyond the eyes. Placerville, CA: L. Harrell Productions, 51-54.
- Houliston, M. J., Taguri, A. H., Dutton, G. N., & Young, D. G. (1999). Evidence of cognitive visual problems in children with hydrocephalus: A structured clinical history-taking strategy. Developmental Medicine & Child Neurology, 41, 298-306.
- Hyvarinen, L. (2004, March). Understanding the behaviours of children with CVI. Paper presented at the webcast for SKI-HI Institute, Utah State University, Logan, UT.
- Jan, J. (2004). An international classification of neurological visual disorders in children, http://www.aph.org/cvi/articles/jan_1.html
- Jan, J., & Groenveld, M. (1993). Visual behaviors and adaptations associated with cortical and ocular impairment in children. Journal of visual impairment and blindness (JVIB), 87, 101-105.
- Jan, J. E., Groenveld, M. G., Sykanda, A. M., & Hoyt, C. S. (1987). Behavioral characteristics of children with permanent cortical visual impairment. Developmental medicine & child neurology, 29, 571-576.
- Morse, M. T. (1990). Cortical visual impairment in young children with multiple disabilities. Journal of visual impairment and blindness (JVIB), 84, 200-203.
- Morse, M. T. (1999). Cortical visual impairment: Some words of caution. RE:view, 31, 21-26.
- Roman-Lantzy, C. (2007) Cortical Visual Impairment: An Approach to Assessment and Intervention. AFB Press, New York: 1-172.

IPAD APPS FOR CVI

Sensory
Electra
Fluidity
I Love Fireworks lite
Art of Glow
Draw Stars
Sensory Room
Baby Bubbles

EDA Play Toby – vision, touch, integration, cause and effect
Infant Zoo – vision, touch integration, cause and effect
Peekaboo HD - Peekaboo Barn lite – vision touch integration, cause and effect
Peekaboo Barn lite – vision touch integration, cause and effect
Tap-N-See-Now – Peekaboo Barn lite – vision touch integration, cause and effect
Hide & Peep

CVI TRAINING
CVIHuman Face
CVITraining/Color
CVITraining/Pattern
CVITrainingRec

Choice Board Creator
Toya Tap Match and Learn
Youdoodle
Youdoodle+