
Resources for Parents of Children with Visual Impairments

WELCOME:

This guide highlights current and readily available resources for parents of young children with blindness, visual impairment, or visual impairment with multiple disabilities.

PARENTING AND GENERAL INFORMATION:

Alsop, Linda. *Understanding Deafblindness: Issues, Perspectives, and Strategies*. North Logan, Utah: Ski-Hi Institute, Hope Publishing, Inc., 2002. 918 pp. Print only, looseleaf binders (2 volumes), \$175. Available from Hope Publishing : <http://hopepubl.com>

While this title is expensive, it may be the best single source for “parents, interveners, and service providers working with children and young adults who are deafblind and their families. It covers all aspects of deafblind programming including communication, concept development, vision, hearing, family issues, touch, sensory integration, intervener role and services, physical education, additional disabilities, orientation and mobility, community support, and evaluation. It contains clear and informative presentations with helpful summaries and many illustrations.” (from the publisher’s website.)

Ferrell, Kay Alicyn. *Reach Out and Teach: Helping Your Child Who is Visually Impaired Learn and Grow 2nd edition*. New York, New York: American Foundation for the Blind, 2011. 445pp. Available from the American Foundation for the Blind : <http://www.afb.org/store>. Paperback (\$49.95), online (\$30), or digital in ASCII text, ePub, or Kindle formats (\$34.95).

This parent-focused guide from AFB updates their classic work from 1985. The new edition includes extensive updated information and resources, details on assistive technology, and strategies for advocacy, understanding applicable laws, and much more. Divided into sections based on age group with many activities, resources, experiences, and summaries of relevant research.

Holbrook, M. Cay, ed. *Children with Visual Impairments: A Parents’ Guide, 2nd edition*. Bethesda, Maryland: Woodbine House, 2006. Print only. Title is out of print, but still readily available from used book sellers. ISBN: 978-1890627409.

The first edition (1996) and second edition (2006) of this title are both excellent resources. Topics include an overview of visual impairment and treatments, emotional impact on family

and siblings, development, and daily life. Includes practical and straightforward advice about nurturing the child's self-esteem, literacy, mobility, and independence.

Freeman, Peggy. *Deafblind Disabled Baby: Program of Care for Parents of the Deafblind Baby with Multiple Disabilities*. Download at <https://nationaldb.org/library/page/1973>, 2001.

The author is both the mother of a deafblind daughter and a teacher of students with deafblindness. Aimed at parents of an infant with deafblindness, this book offers excellent advice for bonding, establishing communication, and stimulating sensory development.

Nieman, Sandy and Jacob, Namita. *Helping Children Who Are Blind: Family And Community Support for Children with Vision Problems*. Berkeley, CA : The Hesperian Foundation, 2000. Available online (free) at http://en.hesperian.org/hhg/Helping_Children_Who_Are_Blind. Also available in paperback (\$15) and PDF (free), and in English, French, and Spanish.

This book comes from a non-profit organization that provides health and community education support worldwide. Using simple line drawings and many examples, it provides a wide range of activities for parents of children who are blind or visually impaired. Emphasis is on using readily available materials and incorporating learning and skill development into daily activities.

WEBSITES:

[BlindBabies.Org](http://www.blindbabies.org/) (<http://www.blindbabies.org/>) offers excellent online resources, particularly about diagnoses and strategies.

[Blind Children](http://www.blindchildren.org) (<http://www.blindchildren.org>) has resources for parents of children who are visually impaired. Includes short essays about a variety of topics from general information to education, to independent movement and travel.

[Family Connect](http://www.familyconnect.org/) (<http://www.familyconnect.org/>) from the American Foundation for the Blind focuses on connecting parents of children with visual impairment with resources and community support. The site includes message boards, tips, and resources for children at different ages.

[National Federation of the Blind resources for parents](https://nfb.org/parent-resources) (<https://nfb.org/parent-resources>) includes information on a mailing list for support and discussion as well as linking to a range of other parent resources.

The [Perkins eLearning site](http://www.perkinselearning.org/) (<http://www.perkinselearning.org/>) is aimed at educators, but can be a great resource for parents as well. Includes videos, lesson guides, and other material.

The [Scout Information Clearinghouse](http://www.perkinselearning.org/scout) (<http://www.perkinselearning.org/scout>) collects links to high-quality online resources. They are sorted by topic, and the "Ask Scout" feature allows you to submit your own questions. Links are selected by Perkins staff.

[WonderBaby.org](http://www.wonderbaby.org/) (<http://www.wonderbaby.org/>) is dedicated to helping parents of children who have visual impairments or multiple disabilities. This Perkins-hosted site has sections on parenting, child development, apps and education, eye conditions, and international information. Offers a community section where parents can connect with other parents.

The [National Center on Deaf-Blindness](https://nationaldb.org/) (<https://nationaldb.org/>) provides resources, resource lists, data, and other materials about those who are deafblind. Includes links to state level programs and agencies, profiles of people who are deafblind, and much more.

FAMILY LIFE AND SIBLINGS:

Chapuis, Deborah K. *In Celebration of Grandparenting: For Grandparents of Children with Visual Impairments*. Watertown, Mass.: Perkins School for the Blind, 2000. 63pp. Available from Perkins Solutions : <http://perkinsproducts.com>. Print, braille, electronic braille (.brf), and Spanish versions, all \$20.

Emphasizing the unique and supportive role of grandparents, this book aims "to address possible concerns and to help appreciate some of the unique joys of grandparenting a child with visual impairment." - Perkins Publications website.

Klein, Stanley D. and Kemp, John D. eds. *Reflections from a Different Journey: What Adults with Disabilities Wish All Parents Knew*. New York: McGraw-Hill, 2004. Print (varied prices), and Kindle (\$13.17).

Essays written by adults with disabilities, including visual impairment. The authors share their experiences and offer advice and encouragement to parents.

McHugh, Mary. *Special Siblings: Growing Up with Someone with A Disability (revised edition)*. Baltimore, Brookes Publishing Co., 2003. Available from Brookes Publishing Co. : <http://products.brookespublishing.com>. Paperback only, \$24.95.

The author weaves together her own experiences as the sister of a man with multiple disabilities with research and interviews with over 100 other siblings and experts. Discusses the needs of siblings at different stages of life, and ways to support and talk about challenges.

Meyer, Don. *The Sibling Slam Book: What It's Really Like to Have a Brother or Sister with Special Needs*. Bethesda, MD : Woodbine House, 2004. Available from <http://woodbinehouse.com>. Paperback only, \$15.95.

Don Meyer is the Director of the Sibling Support Project, which focuses on providing workshops and resources to support siblings of children with special needs. This title collects brief thoughts on a number of topics from pre-teen and teenage siblings.

Meyer, Don. *Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs*. Bethesda, MD : Woodbine House, 1997. Available from <http://woodbinehouse.com>. Paperback only, \$15.95.

While this title is two decades old, it is still a thoughtful, child-friendly, and engaging introduction for siblings. The book is short comments (a page or two each) written by siblings who were ages 4 to 16 at the time, including multiple siblings from the same family.

WEBSITE:

[The Sibling Support Project](https://www.siblingsupport.org/) (<https://www.siblingsupport.org/>) provides workshops, materials, and online community spaces for siblings of children with special needs.

LITERACY:

Beginning in January 2016, the United States and other English-speaking countries use Universal English Braille (UEB) as the standard braille format. Books and resources from before this transition refer to older forms of braille with some differences from UEB. New materials focusing on UEB are forthcoming from a number of sources.

Castellano, Carol. *Because Books Matter: Reading Braille Books with Young Blind Children*. Boston, MA: National Braille Press, undated. 27pp. English and Spanish versions. Available from <http://www.nbp.org/ic/nbp/publications/>. Free (inquire for cost for multiple copies).

This brief booklet is a wonderful introduction to how to introduce young children to braille books. It suggests many activities parents and children can do together. A great resource for other adults in a child's life as well.

Castellano, Carol and Kosman, Dawn. *The Bridge to Braille: Reading and School Success for the Young Blind Child*. Baltimore, MD: National Organization of Parents of Blind Children, 1997. 191pp. Spiralbound, available used from various sellers. ISBN: 978-1885218087.

While this is an older title, it is a practical step-by-step guide that shows parents how to guide their children toward literacy. Topics include adapting materials, beginning braille reading, doing math in braille, resources, and about braille books.

Curran, Eileen. *Just Enough to Know Better (UEB)*. Boston, MA: National Braille Press. 2016. Large print/Braille edition. Available from <http://www.nbp.org/ic/nbp/JETKB-UEB.html>. \$20.00.

This 2016 update of one of the classic titles for parents about braille has been revised for the transition to UEB. It is designed for parents who want to help their children learn to read braille, and covers the braille alphabet, numbers, contractions, and those tricky exceptions to rules. Includes exercises in braille.

Kent, Deborah. *Because Pictures Matter: A Guide to Using, Finding, and Creating Tactile Imagery for Blind Children*. Boston, MA: National Braille Press, undated. 27pp. English and Spanish versions. Available from <http://www.nbp.org/ic/nbp/publications/>. Free (inquire for cost for multiple copies).

Similar to *Because Books Matter*, listed above, this brief booklet gives ideas and activities for exploring tactile images. Suitable for parents and adult friends of the child.

Swenson, Anna M. *Beginning with Braille: Firsthand Experiences with a Balanced Approach to Literacy (2nd edition)*. New York, NY : American Foundation for the Blind, 2016. 442 pp. Available from <http://afb.org/shop>. Paperback (\$55.95) or digital ePub or Kindle formats (\$41.95).

This new edition takes the comprehensive work of the first edition and updates it for UEB. While designed for teachers, it includes a number of exercises, activities, and ideas that parents may find helpful in working with their children.

Wright, Suzette and Stratton, Josephine M. *On the Way to Literacy: Early Experiences for Children with Visual Impairment (2nd edition)*. Louisville, KY: American Printing House for the Blind, 2007. 362 pp. Available from <https://shop.aph.org/>. Print (\$54) and braille (\$137) formats. Both include a CD of accessible files in BRF, HTML, text, PDF, and OPF formats.

This handbook goes with APH's line of emergent literacy materials, but is extremely useful on its own. It discusses each stage of literacy development and provides many practical tips and activities parents can do with their children.

WEBSITES:

The [American Printing House for the Blind](http://aph.org/products) (<http://aph.org/products>) provides braille material to fill school need throughout the United States, but also offers a wide range of other books, teaching items, and products of interest to visually impaired children and their parents. Catalog in multiple formats, as well as an online shopping site.

[BrailleBug](http://braillebug.afb.org/) (<http://braillebug.afb.org/>) from the American Foundation for the Blind introduces children to braille. It has simple games and resources to introduce braille to both sighted and visually impaired children.

[National Braille Press](http://www.nbp.org/ic/nbp/publications/category_browse.html) (http://www.nbp.org/ic/nbp/publications/category_browse.html) provides braille books (including a book of the month club for children) for children and adults, as well as tactile graphics and related products.

[Paths to Literacy](http://www.pathstoliteracy.org) (<http://www.pathstoliteracy.org>) is a site focused on literacy in all forms. It includes strategies, resources, discussions, lesson ideas, along with tip sheets and links to other sources of information. The Emergent Literacy section is most relevant to younger children. A collaboration between Perkins and the Texas School for the Blind and Visually Impaired.

BRAILLE BOOKS AND LEARNING MATERIALS:

Sources for braille books:

- [Braille storybook resources](https://nfb.org/nopbc-braille-storybook-resources) : National Federation of the Blind
<https://nfb.org/nopbc-braille-storybook-resources>
- [Great Expectations Program](http://www.nbp.org/ic/nbp/programs/gep/ge_index.html) : National Braille Press
http://www.nbp.org/ic/nbp/programs/gep/ge_index.html
- [Sources for Children's Tactile Books and Books in Print/Braille and Braille](http://www.aph.org/dolly-partons-imagination-library/sources/) : APH
<http://www.aph.org/dolly-partons-imagination-library/sources/>
- [Sources of free braille books](http://www.pathstoliteracy.org/resources/sources-free-braille-books) : Paths to Literacy
<http://www.pathstoliteracy.org/resources/sources-free-braille-books>

Learning materials:

- [Braille Information for Parents](https://nfb.org/braille-parents) : National Federation of the Blind
<https://nfb.org/braille-parents>
- [Dots for Families](http://www.pathstoliteracy.org/dots-families) : Focuses on braille learning and resources
<http://www.pathstoliteracy.org/dots-families>

- [UEB Online](http://uebonline.org) : Australian UEB braille training course for sighted users.
<http://uebonline.org>
- [Resources for learning UEB](http://www.pathstoliteracy.org/blog/welcome-ueb-resources-learning-new-braille-code) : Paths to Literacy resource list
<http://www.pathstoliteracy.org/blog/welcome-ueb-resources-learning-new-braille-code>

OTHER MATERIALS:

[The National Library Service for the Blind and Physically Handicapped](https://www.loc.gov/nls/) or NLS

(<https://www.loc.gov/nls/>) administers a program of braille and audio materials for eligible borrowers throughout the United States in cooperation with regional or state library services for the blind and visually impaired. The NLS website has additional information about eligibility and how to identify the appropriate library for services. Materials are provided through the mail, so you do not need to be physically near a library to use materials.

EDUCATION/ADVOCACY/EARLY INTERVENTION:

Bringing It All Back Home Project. *HomeTalk: A Family Assessment of Children Who Are Deafblind*. Monmouth, Oregon: 2003. Free. Available in English and Spanish at <https://nationaldb.org/library/page/789>.

An assessment tool for parents of children who are deafblind with other disabilities. Designed to help develop an Individualized Education Plan (IEP), help review progress at school meetings, introduce the student to new staff members, and summarize important information that professionals need to know about the student.

Castellano, Carol. *Getting Ready for College Begins in Third Grade: Working Toward an Independent Future for your Blind/VI Child Pre-K to Middle School*. Charlotte, NC : IAP – Information Age Publishing, 2007. Available from IAP: <http://www.infoagepub.com>. Paperback (\$24.99) or hardcover (\$85).

Focuses on how to make sure a child's education begins and stays on track, and how to create a remediation plan effectively if one is necessary. Chapters include high expectations, academics, independent living skills, independent movement and travel, social awareness and social skills, as well as developing self-advocacy skills.

Chen, Deborah and Downing, June. *Tactile Strategies for Children Who Have Visual Impairments and Multiple Disabilities: Promoting Communication and Learning Skills*. New York, New York: American Foundation for the Blind, 2006. 192 pp. Available from the American Foundation for the Blind : <http://www.afb.org/store>. Paperback (\$39.95), online (\$24), packet (\$89.95), digital in ASCII text, ePub, or Kindle formats (\$34.95).

A good source for parents looking for techniques. Topics include how to assess a child's tactile skills, how to interact effectively, and plan interventions.

Falvey, Mary A. *Believe in My Child with Special Needs: Helping Children Achieve Their Potential in School*. Baltimore: Brookes Publishing Co., 2005. Available from multiple sources, ISBN 1-55766-702-0.

"...[P]arents of a school-age child with a disability need this upbeat, reassuring handbook – to demystify complicated issues, help them celebrate their child's abilities and recognize possibilities, and show them how to be successful advocates throughout their child's education." – Back cover.

Haynes, Diane and Grisham-Brown, Jennifer. *Reach for the Stars: Planning for the Future, a Process for Planning Positive Transitions for Young Children with Disabilities*. Louisville, KY: American Printing House for the Blind, 2007. 86 pp. Available from <https://shop.aph.org/>. Spiralbound (\$20) and braille (\$25) versions. Both include a CD with accessible files in multiple formats.

This guide focuses on person-centered planning adapted for use with young children with disabilities, helping parents and professionals create meaningful goals, plans, and arrange the necessary support and assistance for the child. Examples throughout.

Heydt, Kathy (ed). *Welcoming Students with Visual Impairments to your School: A Guide to Training Public School Personnel and Families about the Needs of Students with Vision Loss*. Watertown, MA : Perkins School for the Blind, 2006. 250pp. binder and 12 CD-ROMs. Available from Perkins Publications: <http://www.perkinsproducts.org>. \$35.

This binder and collected presentations offer four modules (Challenges and Supports, Social Skills, Orientation and Mobility, and Low Vision) for teachers and others in public school settings. Many of the authors are Perkins staff.

LaVenture, Susan (ed). *A Parents' Guide to Special Education for Children with Visual Impairments*. New York, New York: American Foundation for the Blind, 2007. 416 pp. Available from the American Foundation for the Blind : <http://www.afb.org/store>. Paperback (\$34.95), online (\$21), digital in ASCII text, ePub, or Kindle formats (\$24.95).

This book provides extensive detailed information for parents looking for help navigating special education supports in the United States. Includes detailed examples of forms, sample conversations and responses, and additional reading on specific topics.

Crane, Pamela, Cuthbertson, Diana, Ferrell, Kay Alicyn, and Scherb, Hazel. *Equals in Partnership: Basic Rights for Families of Children with Blindness or Visual Impairment*. Undated. Available from Perkins Solutions : <http://perkinsproducts.com>. Print, braille, electronic braille (.brf) versions, all \$20.

Compilation of educational advocacy materials for children who are blind or visually impaired. A solid overview for parents navigating educational and other programs. Some material may be superseded by more recent information or changes to law.

WEBSITES AND ORGANIZATIONS:

The two major US advocacy groups formed by people who are blind and visually impaired to advocate for their own interests and needs are the [National Federation of the Blind](http://nfb.org) (<http://nfb.org>) and the [American Council of the Blind](http://acb.org) (<http://acb.org>). Both have information about current advocacy projects, laws under consideration, and other topics of interest.

The [American Foundation for the Blind](http://afb.org) (<http://afb.org>) is a broadbased organization providing resources (such as a directory of blindness organizations on the state and local level, listed below), career resources, forums, and other materials. Helen Keller acted as a spokesperson for the AFB from the time it was founded, and they also hold most of her adult papers.

In Canada, the [Canadian Council of the Blind](http://ccbnational.net/fresco/) (<http://ccbnational.net/fresco/>) serves the same purpose.

Many states and regions have their own advocacy and support groups. These can often be found through the [AFB Directory](http://www.afb.org/directory.aspx) (<http://www.afb.org/directory.aspx>) or through state or province sites for services for the blind and visually impaired.

The [National Organization of Children with Visual Impairments](http://www.lighthouseguild.org/programs-services/education/napvi) or NAPVI (<http://www.lighthouseguild.org/programs-services/education/napvi>) is focused on supporting and connecting parents in particular.

THE HAYES RESEARCH LIBRARY:

SEARCH OUR CATALOG:

The titles listed here are only some of the materials in the Hayes Research Library. You can use the terms below to [search our catalog](http://www.perkins.org/reslibcatalog) at <http://www.perkins.org/reslibcatalog> to find other titles, journal articles, and resources.

- Child development
- Children
- Communication
- Education
- Family life
- Multiply disabled
- Parent-child relationship
- Parenting
- Psychological aspects
- Services for.

Items do not circulate outside of Perkins, but we can often provide scans of a particular book chapter, journal article, or other materials (such as the table of contents or a bibliography). We also welcome visitors to the Research Library.

ABOUT THE LIBRARY:

The Samuel P. Hayes Research Library at the Perkins School for the Blind is one of the largest non-medical collections about blindness and blindness education open to the public. We welcome questions from anyone interested in the topic, whether they are a parent, teacher, student, researcher, or member of the general public.

Our collection has over 48,000 items. It includes books, journal articles, journals, newsletters, pamphlets, multimedia items, and much more. You can reach Jennifer Arnott, the Research Librarian at hayeslibrary@perkins.org or 617-972-7250. [More about the library is available](http://www.perkins.org/researchlibrary) at <http://www.perkins.org/researchlibrary>.