

A Strong Beginning

A Sourcebook for Health and Education
Professionals Working with Young Children
who are Visually Impaired or Blind

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Title

A Strong Beginning: A Sourcebook for Health and Education Professionals Working with Young Children who are Visually Impaired or Blind.

The Canadian National Institute for the Blind

Editors

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From a Child's Perspective ...

An important consideration for all of us is our perspective. But how does a disabled child see the world? How does his world really differ from ours?

Hi. I am many things, but most important, I'm just a kid. I like to have fun, play games, and be silly. Sometimes you may not understand that I am being silly, but I am. Sometimes I play games with you and you do not understand, but my Mom does. She knows when I get that look in my eye and when I want to just giggle because it feels good. She understands which cry means what and knows just what to do. I can be mad at her, and she loves me anyway. I have the right to be mad. Just imagine not being able to speak or move your arms when you want to pick something up. Think about how frustrated I must feel. Most of the time I am very patient. I have to be. And when I'm not, please understand that it's not easy being in this body and not able to do things I so badly want to do.

Did you ever feel like crying just because you are frustrated, tired, or need a break? Did you ever have an itch that you couldn't scratch? Well, sometimes I have itches, pains, and discomforts and I can't tell you. Help me by being aware that I, too, may have these sensations, and give me the relief I need. It's very soothing to have my shoulders rubbed or my arm stroked or scratched, but I am at your mercy as to when I can have these things. So ask me and ask me often, please.

I am a person. I am funny, I am happy. I have my own likes and dislikes. Let me choose my clothes, my shoes, my dinner, and my activities. Give me a choice, listen to me, and I will prove myself. Let me be me, but help me be more. Be my friend, my guide, and I will give you back so much more than you gave. Listen to me, and don't judge me by my frailties, but by my strengths. I am differently abled, not helpless. Be my friend and I will be yours.

Written by the mother of a 9-year-old boy who is visually impaired and has multiple disabilities.

The views expressed herein do not necessarily represent the official policies of Health Canada.

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Foreword

It takes a great deal of expertise and planning to ensure that children who are visually impaired or blind have the opportunity to participate in high-quality programs that will stimulate their development. The critical importance of a team of knowledgeable professionals cannot be overstated. Children who are blind or visually impaired and their families have the right to have access to professionals with specific expertise and understanding about this unique and relatively rare disability. But access to professionals with qualifications in visual impairment is not enough.

To adequately support each child with unique and sometimes complex needs, we must create a team of people who can address all the child's needs in the context of the visual impairment. In addition to family members and professionals trained in visual impairment, the team will include practitioners with specific training in other fields such as occupational therapy, physiotherapy, speech therapy, nursing, ophthalmology, clinical low vision, social work, general education, or preschool education. In addition, an extended team supports the many children with visual impairments who have other disabilities that have an impact on learning and development. It is for all these professionals that this sourcebook is primarily intended.

Throughout my career as a teacher of students with visual impairments, I have been fortunate to work with a wide variety of professionals. My experience with educational and community-based teams has taught me the value of examining issues from many points of view. I have learned that those with limited training or experience working with children with visual impairments may not be immediately comfortable dealing with blindness. The general public has many misperceptions about blindness. It seems we all believe we can understand what it is like to be blind — we can close our eyes and imagine. In reality, this is not a good simulation. Total blindness is less common than low vision. Wearing a blindfold is a temporary condition and offers no real understanding of adaptations. Dispelling these misperceptions is important for creating cohesive, effective teams. Bringing a greater understanding to team members can go far in creating long-term relationships and in handling difficult situations with compassion and sensitivity. The most effective professionals are those who take a keen interest in each child and have a thirst for information about ways to provide the most effective service possible.

On an effective team, members share expertise. This sourcebook supports the sharing of information about visual impairment. Anyone working with a child who is visually impaired or blind (i.e., parents, rehabilitation teachers, orientation and mobility specialists, or teachers of students with visual impairments) will welcome this book in a home or professional library.

Children who are blind or visually impaired live in all types of communities. The challenges facing these children and their families are similar, regardless of where they may live. As is the case for all children, children who are blind or visually impaired want to learn and grow into happy, healthy, productive people. For some children, this requires additional help along the way.

The publication of **A Strong Beginning: A Sourcebook for Health and Education Professionals Working With Young Children Who Are Visually Impaired or Blind**

comes at a time when funding is low and service for children with disabilities is being cut dramatically in some communities. This book provides an important resource that can help professionals and families increase knowledge and understanding about the impact of visual impairment on the development of young children.

The Canadian National Institute for the Blind has published this valuable resource to help those who are knowledgeable in their own field, but may know little about visual impairment and its impact on development. Readers will increase their general knowledge about visual impairment and will gain specific information about a particular child they are working with. This book presents information in a direct, respectful, and easy-to-understand manner, and readers will enjoy the parent statements and “pearls of wisdom” sprinkled throughout the text.

The goal, for all children, should be to create an environment where they can learn and grow to their full potential. By surrounding children who are visually impaired or blind with a community of knowledgeable professionals, I believe we will succeed.

Cay Holbrook, PhD
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Preface

WHY A SOURCEBOOK?

For many years, professionals across Canada have been committed to meeting the needs of young children who are visually impaired or blind, and their families. While travelling across the country, we have met CNIB staff working on teams with health-care professionals, educators, and parents. Attempting to address specific issues faced by these children, it became clear that there is a significant lack of information about vision impairment and its impact on a child's development. In May–June 2002, the CNIB national office hosted a two-week training program for CNIB and other early intervention service providers. The program curriculum was designed by Kevin Stewart, PhD, co-author of Chapter 7: Learning Through the Senses, and brought together many of the experts who have contributed chapters to this sourcebook. A book of readings was created for the course, and an American text was used, as no Canadian source existed. In July 2002, the CNIB published the long-awaited handbook for parents, **Finding a New Path**, but what kind of resources existed for professionals?

ESTABLISHING THE NEED

Through a literature search, we found that the majority of existing resources were aimed at parents or educators of children with visual impairments, yet few were aimed at other professionals (i.e., clinicians, community-based service providers, regular preschool/-classroom teachers). For many people, the field of blindness and visual impairment is perceived as very narrow, very specific, and not very accessible. It was time to bridge this information gap and to develop a book that would provide much-needed information to these professionals.

INTENDED USERS

We envisioned a predominately Canadian-produced sourcebook for professionals who:

- are experts in their own fields, but know very little about visual impairment and its impact on development
- may not have a formal education in the subject but have daily interaction with children who are blind or visually impaired and their families
- know a particular child very well but do not have an understanding of the basic concepts in the field of blindness and visual impairment
- are attempting to adapt their procedures, including assessment and treatment plans, without knowledge of the resources available to them
- work with children who have a multitude of disabilities, but for whom the visual impairment has not been taken into account

We created a proposal for the Population Health Fund of Health Canada, and in the fall of 2002, this project was born. It has been a very exciting initiative.

THE REVIEW PROCESS

We selected a process that would:

- bring together many professionals across the country to provide feedback on the sourcebook and to learn from each other
- facilitate the development of a national network of professionals working with children with visual impairments

More than 230 reviewers, representing a broad range of disciplines (see Acknowledgements), reviewed a draft copy of the sourcebook. Reviewer workshops were held in 18 Canadian cities, and those living in remote areas were invited to participate in the process by teleconference. We believe this rigorous review process has been the single most significant factor in producing a truly practical sourcebook for use by practitioners in their day-to-day work with children.

This sourcebook is designed to:

- provide professionals and students with current information regarding vision impairment and its impact on early childhood development
- serve as a reference guide for information related to low vision in the young child
- offer strategies to use in working with the family or teaching a child who is blind, visually impaired or deafblind, with or without additional disabilities, from birth to 5 years of age

Children who are visually impaired, and especially those with additional disabilities, require innovation and imagination from the professionals in their lives. The contributors to this book share a combined experience of many, many years working with these children, to assist you in your work. We hope that you find this sourcebook useful and that it begins to fill the identified gap in information.

Deborah Gold

Anne Tait

About the Editors

Deborah Gold, PhD, is national manager, program development, at The Canadian National Institute for the Blind, where she is responsible for the development of training, research, and information projects. She is the principal investigator on several national research projects, including a national study of youth and a national needs study of people in Canada who are blind or visually impaired. She oversees a national research project on the vision care needs of Aboriginal Canadians and a national social policy research project on access to low vision services for seniors. Deborah holds a PhD in Special Education from Syracuse University (1995), focusing on social policy and disability, and has worked as a residential counsellor, recreation counsellor, researcher, and educator. Her primary research interest has been social inclusion, and she has published several books and articles relating to leisure and the social construction of friendships.

Anne Tait, RN, BScN, joined the CNIB in September 2002, as project coordinator and developmental editor for this sourcebook. In this role, she recruited key reviewers, facilitated the reviewer workshops across Canada, and worked closely with the chapter contributors and project national advisory committee during all phases of the book's development. A former community health nurse, Anne has also worked in non-profit management with several national health charities, focusing on training and development, project management, strategic planning, and board governance initiatives. She recently participated in a team effort to research and develop evidence-based best practice guidelines for nurses. Anne's personal interest in writing, copy editing, and the editorial process has led to the completion of several journalism and publishing courses at Ryerson University in Toronto.

About the Contributors

Asim Ali, MD, completed an MD from the University of Toronto in 1999 after an undergraduate degree in Electrical Engineering from the University of Waterloo. He is presently chief resident in ophthalmology at the University of Toronto and will be doing a fellowship in pediatric ophthalmology and strabismus in the US next year. He plans to pursue a career in pediatric ophthalmology upon his return to Canada.

Tanni Anthony, PhD, is the Colorado State consultant on visual impairment and the project director of the Colorado Services for Children With Combined Vision and Hearing Loss. She is a certified teacher of students with visual impairments and an orientation and mobility specialist who specializes in young children who are blind or visually impaired. Tanni earned her PhD in Child and Family Studies from the University of Denver.

Len Baker, BA (Ed), is the director of rehabilitation for the CNIB in Atlantic Canada. Len joined the CNIB in 1991 as the coordinator of the Summer Intervention Program for the Newfoundland and Labrador Division. In 1993, he became the child and family counsellor for the division. Len obtained a BA (Ed) degree from Memorial University of Newfoundland and Labrador in 1986. He currently lives in St. John's with his wife and two daughters.

Ray Buncic, MD, FRCSC, is a medical graduate of McGill University (1965). He studied ophthalmology in Toronto and neuro-ophthalmology in San Francisco. His main interest has been in pediatric neuro-ophthalmology, which he has practised at the Hospital for Sick Children in Toronto since 1972. He led the ophthalmology department there as the chair until 2003. Currently he is professor of ophthalmology at the University of Toronto and acts as a consultant at the Bloorview Macmillan Rehabilitation Centre. In 2002, the Children's Eye Group in the UK awarded Dr. Buncic the inaugural Claude Worth Gold Medal for international leadership in pediatric ophthalmology. He has a special interest in the medical, educational, and social needs of children who are visually impaired.

Deborah Chen, PhD, is a professor in the College of Education at California State University, Northridge, where she teaches in the master's and credential programs in Early Childhood Special Education. She has worked with families and young children with visual impairments, as a service provider and program administrator. She has directed several projects funded by the US Department of Education related to professional development in early intervention and has worked with families of diverse cultural and linguistic backgrounds. Her research and publications have focused on young children with visual impairments and additional disabilities and effective practices in working with families from diverse cultures.

April Cornell, MEd, is the executive director of the Ontario Foundation for Visually Impaired Children (OFVIC), Toronto. She has been active in the field of early childhood special education for 28 years in community-based agencies, the past 10 years with young children with visual impairments. She has been a part-time instructor at Toronto-area community colleges, in the Post-Diploma Early Childhood Education/Special Needs Programs. She has written and presented on the learning styles of young children with visual impairments, with and without additional disabilities. She has also co-authored *Exceptional Children: Inclusion in Early Childhood Programs* (Canadian Edition).

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Pennie Jevnikar is the mother of three daughters; two were born prematurely and developed retinopathy of prematurity (ROP). One daughter reads large print, the other is a braille user, and all three daughters attended mainstream programs in neighbourhood schools. Pennie is one of six founding board members of *Child Light: A Parent Resource for Blind and Visually Impaired Children*. Pennie is married, lives in London, Ontario, and is a dentist in her professional life.

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Ann MacCuspie, PhD, is the director of programs for students who are blind or visually impaired at the Atlantic Provinces Special Education Authority (APSEA), an interprovincial organization providing educational services, programs, and opportunities for persons from birth to 21 years of age with low incidence sensory impairments (i.e., children and youth who are blind, visually impaired, deafblind, deaf, or hard of hearing). During her 30-year career in the field of blindness, Ann has worked as an itinerant teacher, classroom teacher at the former Halifax School for the Blind, consultant, and coordinator of provincial services. She is an adjunct honorary professor at several universities where she teaches graduate courses for teachers studying to become teachers of students who are blind or visually impaired.

Carolyn Monaco has worked in the field of deafblindness since 1978, as a residential school intervenor and counsellor, a community school intervenor, a provincial resource consultant for students who are deafblind, and an instructor/consultant with the Skills Training and Resource (STAR) Centre at the W. Ross Macdonald School. Carolyn presently works as an instructor in the intervenor for deafblind persons program at George Brown College in Toronto. She has been very involved with The Canadian Deafblind and Rubella Association (CDBRA) for a number of years. Carolyn was the recipient of the 2002 AER (Division III) Samuel Gridley Howe Award for outstanding practice in services for individuals with deafblindness and multiple disabilities and their families, and is the author of several book chapters.

Duncan McGregor, EdD, is an itinerant vision teacher and certified orientation and mobility specialist for the York Region District School Board in Ontario and is an instructor in the College of Education (Teacher of the Blind certification) for the University of Western Ontario. He has written a number of chapters in textbooks and articles in professional journals on educating children who are visually impaired and has also presented papers at several regional, national, and international conferences.

Angela Romanyshyn, BSc, B.M.R. (OT), OT (C), has worked as an occupational therapist in the area of pediatrics since 1995, and has been with the early intervention program of the CNIB Manitoba Division since 1998. In this role, she provides intensive assessments, parent education, and individualized programming to assist infants and preschool children. Angie developed and facilitates parent support groups, preschool skills groups, a parent/child sensory group for children with multiple needs, and a music therapy program. She received the Fieldwork Educator Roster of Honour from the University of Manitoba in 2000 and 2003, in recognition of outstanding professional contributions as a role model, fieldwork educator, and mentor.

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Kevin Stewart, EdD, is clinical consultant, Ontario Foundation for Visually Impaired Children (OFVIC), Toronto, where he provides training in early childhood visual impairment and multiple disabilities. He is lead teacher, vision department, York Region District School Board, providing in-service training to teachers of people who are visually impaired, educational assistants, and braillists. Kevin also teaches students with visual impairments with or without additional disabilities, from kindergarten to high school age. He instructs part-time at several universities in Canada and the US, and has been involved in writing pre-service and in-service curricula in early intervention, and in teacher preparation in visual impairment and multiple disabilities. His research and publications focus on the learning styles of young children with visual impairment, and on orientation and mobility.

Millie Trask is the single parent of a child with multiple disabilities and lives in Newfoundland. She is actively involved in The Canadian Association for Families of Children With Visual Impairments (CAFVI) and is currently the provincial representative for Newfoundland/Labrador. She has been involved in several CNIB parent-focused initiatives and continues to be a strong advocate of young children and vision impairment. Millie refers to her 9-year-old son Forrest as “the light of my life.”

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A Strong Beginning: A Sourcebook for Health and Education Professionals Working with Young Children who are Visually Impaired or Blind represents the contributions and efforts of a large number of very talented individuals. First, we thank the chapter contributors (introduced above) for sharing their expertise in this very important field.

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In addition, a number of professionals wishing to remain anonymous took part in this review process.