Children with Vision Impairment

Assessment, Development, and Management

Edited by Naomi Dale, Alison Salt,
Jenefer Sargent, and Rebecca Greenaway

Mac Keith Press Practical Guides

Children with Vision Impairment

Assessment, Development, and Management

Children with Vision Impairment

Assessment, Development, and Management

Edited by

Naomi Dale

Consultant Clinical Psychologist and Paediatric Neuropsychologist, Great Ormond Street Hospital for Children; Professor of Paediatric Neurodisability, UCL Great Ormond Street Institute of Child Health, London, UK.

Alison Salt

Honorary Consultant Paediatrician, Neurodisability Service, Great Ormond Street Hospital for Children; Honorary Associate Professor, UCL Great Ormond Street Institute of Child Health, London, UK.

Jenefer Sargent

Consultant Paediatrician and Speciality Lead, Neurodisability Service, Great Ormond Street Hospital for Children, London, UK.

Rebecca Greenaway

Consultant Clinical Psychologist and Paediatric Neuropsychologist, Great Ormond Street Hospital for Children, London, UK.

2022
Mac Keith Press

Managing Director: Ann-Marie Halligan
Senior Publishing Manager: Sally Wilkinson
Publishing and Marketing Co-ordinator: Paul Grossman
Production Manager: Andy Booth

First published in this edition in 2022 by Mac Keith Press
2nd Floor, Rankin Building, 139–143 Bermondsey Street, London, SE1 3UW

British Library Cataloguing-in-Publication data
A catalogue record for this book is available from the British Library

Cover designer: Marten Sealby

ISBN: 978-1-911612-33-9

Typeset by Riverside Publishing Solutions Ltd
Printed by Hobbs the Printers Ltd, Totton, Hampshire, UK

Contents

PART 1: EYE DISORDERS, VISION, AND BRAIN

PART 2: CHILD DEVELOPMENT AND LEARNING FROM BIRTH TO OLDER CHILDHOOD

PART 3: FURTHER APPROACHES TO HABILITATION

PART 4: SOCIAL RELATIONSHIPS AND PARTICIPATION

Author Appointments

Kim Bates
Speech and Language Therapist, Neurodisability service, Great Ormond Street Hospital for Children, London, UK.

Richard Bowman
Consultant Ophthalmologist, Great Ormond Street Hospital for Children; Honorary Associate Professor, UCL Great Ormond Street Institute of Child Health, London School Hygiene Tropical Medicine, London, UK.

Giulia Cappagli
Post Doctoral Researcher, Unit for Visually Impaired People (UVIP), Istituto Italiano di Tecnologia (IIT), Genova, Italy.

Christopher Clark
Parent of a child with visual impairment, UK.

Kate Clark
Parent of a child with visual impairment, UK.

Michael Crossland
Specialist Optometrist, Moorfields Eye Hospital; Honorary Senior Research Associate, UCL Institute of Ophthalmology, London, UK.

Annegret Dahlmann-Noor
Consultant Ophthalmologist, Moorfields Eye Hospital; Honorary Associate Clinical Professor, UCL Institute of Ophthalmology, London, UK

Naomi Dale
Consultant Clinical Psychologist and Paediatric Neuropsychologist, Great Ormond Street Hospital for Children; Professor of Paediatric Neurodisability, UCL Great Ormond Street Institute of Child Health, London, UK.

Graeme Douglas
Professor of Disability and Special Educational Needs, University of Birmingham, Birmingham, UK.

Elisa Fazzi
Professor of Child Neurology and Psychiatry, Unit of Child Neurology and Psychiatry, ASST Spedali Civili of Brescia; Department of Clinical and Experimental Sciences, University of Brescia, Brescia, Italy.

Monica Gori
Principal Investigator, Unit for Visually Impaired People (UVIP), Istituto Italiano di Tecnologia (IIT), Genova, Italy.

Rebecca Greenaway
Consultant Clinical Psychologist and Paediatric Neuropsychologist, Great Ormond Street Hospital for Children, London, UK.

Andrea Guzzetta
Associate Professor of Child Neurology and Psychiatry, Department of Developmental Neuroscience, IRCCS Stella Maris Foundation; Department of Clinical and Experimental Medicine, University of Pisa, Pisa, Italy.

Jessica Hayton
Lecturer in Psychology; Programme Leader Graduate Diploma in Habilitation and Disabilities of Sight, UCL Institute of Education, London, UK.

Rachel Hewett
Research Fellow, Department of Disability and Special Educational Needs, University of Birmingham, Birmingham, UK.

M Cay Holbrook
Associate Professor, Educational and Counselling Psychology, and Special Education, University of British Columbia, Vancouver, British Columbia, Canada.

Clare Jackson
Clinical Psychologist, Addenbrookes Hospital, Cambridge, UK.

Sabina Kef
Assistant Professor, Faculty of Behavioural and Movement Sciences, Clinical Child and Family Studies, Vrije Universiteit, Amsterdam, the Netherlands.

Mike McLinden
Emeritus Professor of Education, University of Birmingham, Birmingham, UK.

Mariya Moosajee
Professor of Molecular Ophthalmology at UCL Institute of Ophthalmology and The Francis Crick Institute; Consultant Ophthalmologist in Genetic Eye Disease at Moorfields Eye Hospital and Great Ormond Street Hospital for Children, London, UK.

Susan Mort
Practical Skills Tutor, Graduate Diploma in Habilitation and Disabilities of Sight, UCL Institute of Education, London, UK.

Ngozi Oluonye
Consultant Paediatrician, Neurodisability service, Great Ormond Street Hospital for Children; Moorfields Eye Hospital, London, UK.

Els Ortibus
Professor of Child Neurology, Child Neurology Department, University Hospitals Leuven; Department of Development and Regeneration, KU Leuven, Leuven, Belgium.

Jackie Osborne
Qualified Teacher of Children and Young People with Vision Impairment (QTVI), Specialist Advisory Teacher and Vision Impairment Team Manager (Retired), UK.

Jugnoo Sangeeta Rahi
Professor of Ophthalmic Epidemiology, Population, Policy and Practice Research and Teaching Department, UCL Great Ormond Street Institute of Child Health; Honorary Paediatric Ophthalmologist, Great Ormond Street Hospital for Children, London, UK.

Steve Rose
Principal Speech and Language Therapist, Great Ormond Street Hospital for Children, London; Independent SLT and Deafblind Consultant, UK.

Elena Sakkalou
Senior Lecturer in Psychology, School of Psychology and Sports Science, Anglia Ruskin University, Cambridge, UK.

Alison Salt
Honorary Consultant Paediatrician Neurodisability Service, Great Ormond Street Hospital for Children; Honorary Associate Professor, UCL Great Ormond Institute of Child Health, London, UK.

Consultant Paediatrician, Paediatric Rehabilitation Service, Perth Children's Hospital; Clinical Associate Professor, University of Western Australia, Perth, Australia.

Jenefer Sargent
Consultant Paediatrician and Speciality Lead, Neurodisability Service, Great Ormond Street Hospital for Children, London, UK.

Julia Smyth
Occupational Therapist, Great Ormond Street Hospital for Children, London, UK.

Ameenat Lola Solebo
NIHR Clinician Scientist, Population, Policy and Practice Research and Teaching Department, UCL Great Ormond Street Institute of Child Health; Honorary Paediatric Ophthalmologist, Great Ormond Street Hospital for Children, London, UK.

Francesca Tinelli
Postdoctoral Neuropsychologist, Department of Developmental Neuroscience, IRCCS Fondazione Stella Maris, Pisa, Italy.

Holly Tuke
Person with visual impairment, UK.

Simon Ungar
Educational Psychologist, Schools and Community Psychology Service, Wandsworth Council; Academic and Professional Tutor, Department of Clinical, Educational and Health Psychology, University College London, London, UK.

Mathijs Vervloed
Associate Professor, Behavioural Science Institute, Radboud University, Nijmegen, the Netherlands.

Kim T Zebehazy
Associate Professor, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia, Vancouver, British Columbia, Canada.

Foreword

Worldwide the causes of impaired vision are changing, with some ocular causes diminishing and cerebral aetiologies increasing in prevalence. Impairment of sight, or blindness, is rare in children but poses enormous challenges for the affected young people and their families, who very much depend upon skilled professional support from a range of agencies to optimise their chances in life. This book, with its up-to-date broad collection of salient information about the diverse characteristics and needs of children with vision impairment and how to cater for them, provides a welcome contribution to the knowledge and skills needed by the multidisciplinary health, education, and social care practitioners and all those working with children with visual impairment.

The book is divided into four sections which address in turn the range of causes of vision impairment, the impact of vision impairment on child development, approaches to habilitation, and the social consequences of low vision and ways to address them.

Part 1 addresses the wide range of causes and manifestations of low or no vision. An effective way to think about the visual system is from front to back. For children with vision impairment, the optics of the cornea, lens, and the ability to optically accommodate are the first thing to consider. The retina, pixelated as it is by cones for day vision and rods for night vision, digitally converts the focussed visual scene projected upon it into pre-processed electrical data. This information is conducted along the visual pathways to the occipital lobes for primary visual processing of visual clarity, contrast, brightness, colour, visual depth, and visual field perception. Further image processing takes place in the temporal lobes and the posterior parietal lobes. These processes are supported by additional processing in the pulvinar of the thalamus and superior colliculi (injury of which severely compounds cerebral visual impairment). Vision impairments can be due to disorder of any element of this overall process affecting any of the many complex networks involved in the processing of visual information. Part 1 highlights that lack of vision in infants and young children fundamentally impacts upon their learning, and it explains the strategies needed to deal with this risk. During early development the brain has an enormous capacity to adapt and develop, a phenomenon that can potentially be harnessed and encouraged by skilled care and parenting. This fascinating phenomenon is also well reviewed.

As vision is integral to multiple developmental processes, reduced vision may have a wide variety of consequences. For these reasons part 2 of the book highlights the potential impact that impaired vision can have upon social, motor, and language development as well as cognition, and addresses these issues in a clearly presented series of chapters. Identifying, greeting, and meeting up with friends is largely contingent upon vision in the typically sighted person. Much communication, whether in person or online, is enhanced by facial expression and gesture which the listener detects and understands visually. So it is not surprising that reduced vision can interfere with social engagement, with the potential risk of social isolation and consequent mental health issues. Recognition of such risks and ensuring that appropriate advance action is taken is clearly essential. For example, communicating using language and touch that describes the environment to the child or teaching the child's contemporaries about how vision impacts upon communication and what they can do to help prevent such problems arising in the first place. Consequently part 2 culminates in highlighting the fundamental role that parents and other caregivers and educators have in saliently rendering their child's experiences accessible and meaningful.

Children with vision impairments need to gain a range of special skills. Freedom to move around and find one's way gives autonomy and is of course an essential skill, while access to the printed word whether in print or in braille is another fundamental need. Ways to address these challenges are well addressed in part 3.

Part 4 focuses on social participation and quality of life. This section highlights how important it is for those with vision impairment to feel understood, included, and respected, culminating in gaining the sense of self-worth needed to successfully progress into adult life. Children with vision impairments, whether ocular or cerebral in origin, can only learn from what is accessible to them, often relying greatly upon the nature of their soundscape for example. Yet impairment of vision is a hidden disability, meaning that a person with typical sight can easily be unaware or forget that children with vision impairment have different experiences to their own. It is therefore essential that for every child with vision impairment their functional vision is known and understood by as many people as possible, including their school contemporaries. It is essential that their visual needs are understood at a fundamental level and taken into account as comprehensively as possible.

This book is a 'must read' for all developmental and neurodisability paediatricians, paediatric and educational psychologists, occupational therapists, physiotherapists, speech and language specialists, ophthalmologists and eye clinic staff, paediatric neurologists, specialist teachers of the visually impaired child and other educationalists, and family support and social care workers with responsibility for optimising the development and life opportunities of children with no or low vision in order to help bring about this aspiration.

Gordon N Dutton
Emeritus Professor of Visual Science
Glasgow Caledonian University, UK

Preface

Children with vision impairment are children first. They deserve equal rights and opportunities in the contemporary world, from birth to adulthood. This includes access to learning and development of skills for everyday living to enable full participation in social, educational, community, and occupational possibilities (United Nations Convention on the Rights of the Child, 1989). Children with vision impairment need additional support and management of care to achieve these aspirations and ambitions. The physical and social environment must be adapted and structured to support the child's growth, functioning, and participation in society.

This book is designed as a Practical Guide to support practitioners in their management of care of children who have long-term vision impairment and disability. Its main themes are *assessment of the child, the child's function and activity, and habilitation or remedial intervention*.

This Practical Guide aims to provide knowledge and guidance to support practitioners and researchers from all disciplines and backgrounds who need to come together to assist the child and their family from birth until early adulthood. This involves practitioners across health, education, and social care, and is designed to assist those who have specialist skills in vision impairment and those who have other specialist or more generalist skills but need to gain more insights. The book is also relevant to researchers in ophthalmological and vision science, neuroscience, and psychological and social science.

The development of this book was driven by the recognition of the need for a contemporary Practical Guide to support evidence-based practice that would reflect the many developments in theory, research, and practice in the field. Many of us were assisted in our formative years by the ground-breaking textbook of the time, *The Management of Visual Impairment in Childhood*, by Alistair Fielder, Anthony Best, and Martin Bax (Mac Keith Press, 1993). We thank Mac Keith Press, including Ann-Marie Halligan, Sally Wilkinson, Paul Grossman, and Andrew Booth, and Ting Baker and Duncan Potter at Riverside Publishing Solutions, for assisting us in the original vision of the book and their commitment to its development.

Many other people and organisations have also inspired the thinking and content of this book, including Patricia Sonksen, developmental paediatrician, who developed and was first director (1973–2000) of the multidisciplinary Developmental Vision Clinic service at Great Ormond Street Hospital for Children, London, UK. The Developmental Vision Clinic has been running for over 40 years and was one of the first multidisciplinary paediatric neurodisability service to focus on the functional vision and developmental needs of children with severe visual impairment and their families. We aim to bring the ongoing expertise and research insights from this team and that of other international experts to a broad multidisciplinary audience of professionals to assist them in their work with children with vision impairment. We are grateful to the collective faculty of authors of the chapters who have shared their expert knowledge and wisdom, and invested much time in helping advance the current ways of thinking in the book. The unique interdisciplinary academic contexts of the Mary Kitzinger Trust and the European Academy of Childhood Disability have enabled us to learn and grow together.

Our work has been inspired by thousands of children, parents, colleagues in the Developmental Vision Clinic service, and hospital and community practitioners who share their insights and have taught us so much over the years; we thank them all. Thank you to the parents and young people who have generously permitted their photographs and to Medical Illustrations of Great Ormond Street Hospital for photography. Last but not least, we wish to thank our families and friends who have provided loving care, support, practical help, patience, and understanding throughout the writing of the book.

Naomi Dale, Alison Salt, Jenefer Sargent,
and Rebecca Greenaway
November 2021

REFERENCES

Fielder AR, Best AB, Bax MCO (1993) *The Management of Visual Impairment in Childhood*. London: Mac Keith Press.

United Nations Convention on the Rights of the Child. Available at: https://www.ohchr.org/en/professionalinterest/pages/crc.aspx

CHAPTER 21

Personal Experiences from a Young Person

Holly Tuke

BACKGROUND

I was born preterm at 24 weeks, weighing 624 grams, so I was rather tiny! I developed a condition called retinopathy of prematurity, as I needed oxygen to survive, which made my retinas grow too fast and not attach properly. I have stage 5 retinopathy of prematurity as I have a detached retina in my left eye, and only light perception in my right eye, therefore I have no useful vision. With that in mind, I am a braille reader. I can read braille in English, French, and German, as well as braille music. I also use a range of assistive technology.

My mum and dad have never treated me any differently because of my vision impairment, neither have my family and friends, and I think that is very important. With the encouragement of my parents, I have always done the things my sighted friends do, even from a young age.

EDUCATION

I attended mainstream school throughout my education journey. It was definitely a rollercoaster, but I got through it and got the grades that I worked hard for. I had fantastic teaching assistants who put work into an accessible format and supported me in lessons. However, there were many occasions when teachers did not give my teaching assistants the work in time for them to make it accessible, but we tried the best we could and often had to adapt. I think being a confident and proficient user of braille and assistive technology really helped with this. I started learning braille around the age of 4 or 5 years whilst everyone in my class was learning to read and write print. I think that was a great way of doing things, I was still learning like them, just in a different way. I started using assistive technology when I was around 6 or 7 years old, so I have grown up with it. In school I used a mix of braille and digital formats, which I found very useful, I would often use a combination of both. My mum and dad would also try to learn bits of braille and use the screen-reading software alongside me, so that we were all learning together in a way and, looking back, I found that really beneficial.

As I progressed through secondary school, my independence grew, and I would often not have my teaching assistants in lessons with me. We had a system that I was able to get in contact with them if I did need some support. That worked really well; it increased my confidence and independence, but it also made my teachers more aware and hopefully widened their knowledge and experience of working with a student with a vision impairment. There were teachers who did panic at times because they were under the assumption that I had to have someone with me all the time, but when they realised that I could work absolutely fine on my own, their attitudes changed. I know that many students may need support in all lessons and throughout the school day, but it is not the case for everyone so it is very important to promote independence where possible.

School was not plain sailing all the time. I had various issues, and my mum, dad, and I often had after-school meetings with staff to try and resolve issues. If more thought had been put into making lessons more accessible, planning lesson adaptations in advance and understanding what I did and did not need as a learner with a vision impairment then I think that would have made things a lot better all-round. I think it is key to be surrounded by supportive people as this makes such a difference. The teachers who really wanted to understand my disability and took the time to do so really stood out from the rest.

I would have also benefited from more specialist equipment and software during school, including a braille display and braille notetaker, especially during my exams at high school (GCSEs, A levels – UK).

Independence is a huge part of growing up but even more so for blind and visually impaired young people, as we learn independent living skills and mobility. Getting to grips with using the long cane was something I struggled with. I felt like I stood out from everyone else and that it made my disability more visible, but that was not the case at all. The thought of using the cane filled me with dread and anxiety, and I did everything I could not to use it. However, I gradually began to see the benefits and these outweighed the negatives. Finding an extremely supportive mobility officer really changed everything for me; she understood my worries and helped me to turn them around. I think people often do not realise how daunting it can be to use a cane or learn such skills, so it is important to understand this and encourage blind and vision-impaired young people, rather than discourage or force them to do things.

To be honest – I disliked my two final years at school (sixth form – UK). I most definitely felt like an outsider and that my disability was rather prominent so that people did not see me for the person I am, instead they saw my disability. Despite this, I got good final exam results (A levels) and went on to get a place at my first-choice university.

I studied the Children, Young People and Families course at York St John University. I absolutely loved my time there, enjoying my course and making a great set of friends. I was given materials in advance (most of the time) and had support available to me. At university, I definitely got better at advocating for myself as my needs were met, and I became better understood.

EMPLOYMENT

Whilst in my third year of university, I worked for a visual impairment charity for a few hours a week helping set up projects, updating social media, and doing all sorts of tasks. When I graduated, I do not think I was fully prepared for how hard it was going to be to find a graduate job, especially as a young person with a disability. It can be very disheartening when you are job hunting and you come across many jobs that are simply inaccessible. However, I did get a job within 6 months of leaving university and worked as an assistive technology advisor at the university I graduated from for nearly 4 years. I now work within the charity sector as a Social Media Officer for a sight loss charity, this is something that I have had my sights set on for the last few years. It is amazing to be able to support my community.

I have received support from the government ‘Access to Work’ scheme, which funded a screen-reader that I simply could not have done my job without, a braille display, and orientation and mobility training. I love my job; my colleagues understand my vision impairment and see me for the person I am, and not just my disability.

HOBBIES AND INTERESTS

Other than my vision impairment, I am pretty much your average woman in her 20s. I love music, and going to concerts. I enjoy spending time with my friends and family, and I have an interest in beauty and fashion.

When I was at primary school, I started playing the flute and that continued for many years, I was even in a band. I have many fond memories of playing at my local theatre and other venues. I did not let my vision impairment stop me from learning an instrument, and, as a result, I learnt braille music and also to play by ear.

In 2015, I started my blog ‘lifeofablindgirl.com’ in the hope of sharing my experiences of living with a vision impairment, tackle the common misconceptions and stigmas surrounding vision impairment and disability, and also to help other disabled people in any way I can. When I was growing up, there were not really any disabled role models that I could relate to, so I wanted to be that role model in a way. There is no denying that growing up with a disability can be difficult at times, and we all need to know that we are not alone. We all sometimes need someone to relate to or to get some advice from others in the same or similar situations.

My blog has grown a lot over the years and it has gone places I never even thought of. From being named as one of the most influential disabled people in the UK, to being on radio stations, featuring in newspapers and magazines, having the opportunity to write guest posts and articles for various organisations and websites, and becoming an ambassador for a local charity. I have had some incredible opportunities through blogging that I am so grateful for. I cannot quite put into words how it feels to have readers from all over the world!

Every person with a vision impairment is different, we all have our hobbies and interests, strengths, and weaknesses. We all have our likes and dislikes, but most importantly we are not the same. This is just a bit of a snapshot into my life as a blind woman.

What is important to me as a young person with a vision impairment

- ✓ Being encouraged to strive for success and to have aspirations; having a disability is not an obstacle for success.
- ✓ Recognising that every child or young person with vision impairment is different, just like their peers. What works for one person may not work for another.
- ✓ Being listened to and understood.
- ✓ Remembering that vision impairment is a spectrum and it is important for others to understand what a young person can or cannot see.
- ✓ Focussing on the positives of having a vision impairment such as being part of the vision impairment community and proactively acting on these positives.