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Down Syndrome Resources

This month we are featuring books, videos, websites and children's books about Down syndrome.

Down Syndrome - Books

Adolescents with Down Syndrome: Toward a More Fulfilling Life. Siegfried M. Pueschel and Maria Sustrova, 1997. (226.11 P977a 1997 RHB).

This book takes a holistic approach to the issues, focusing on the person with Down syndrome. Experts from diverse backgrounds provide information and perspectives on biomedical, psychological, social, sexual, behavioral, educational, vocational, recreational, and legal concepts.

Another Season—A Coach's Story of Raising an Exceptional Son. Gene Stallings and Sally Cook, 1997. (800.1 S782 1997).

In this biography, the author shares with honesty, perception, and compassion the trials and tribulations of raising his only son who has Down syndrome. This is a glimpse of family life, a few football anecdotes, and poignant lessons with John Mark, the son, the real champion who teaches us what life, not just winning, is all about.

Babies with Down Syndrome: A New Parents' Guide. Karen Stray-Gundersen, 1995. (226.11 Str82 ECI).

This second edition provides a complete introduction to Down syndrome and improves on the original with information on prenatal testing, early intervention, legal medical issues, and resources. Written for parents by parents, doctors, nurses, educators and lawyers, it covers everything parents need to know about raising their child with Down syndrome. [Also available in Spanish, "Bebes con sindrome de Down: guia para padres." 226.11 S913b 1998 ECI]

Changed by a Child: Companion Notes for Parents of a Child with a Disability. Barbara Gill, 1997. (271.4 G41 ECI).

In simple stories of faith, courage, fear, and forgiveness, the mother of a son with Down syndrome describes what parents feel. This book offers parents the reassurance of true understanding.

Children with Down Syndrome: A Developmental Perspective. Dante Cicchetti and Marjorie Beeghly, 1990. (226.11 C848 ECI).

This highly technical book contains theories and research by various experts about young children with Down syndrome. It looks at all aspects of their lives from a developmental framework.

Down Syndrome - Books (continued)

Como Favorecer las Habilidades Comunicativas de los Niños con Síndrome de Down. Lubby Kumin, 1994. (226.11 K96c 1994 ECI).

In this book, "Communication Skills in Children with Down Syndrome: A Guide for Parents," translated into Spanish, an expert shares her knowledge of speech and language development in children and adolescents with Down syndrome including information, advice, and practical home activities.

Continuity and Change in the Social Competence of Children with Autism, Down Syndrome, and Developmental Delays. Marian Sigman and Ellen Ruskin, 1999. (226.5 S577c 1999 ECI).

This monograph describes the results of a longitudinal study which aims were: 1) to assess the continuity and change in diagnosis, intelligence, and language skills in children with autism, Down syndrome, and other developmental delays, 2) to specify the deficits in social competence and language skills in these children, and 3) to identify precursors in the preschool period of gains in language skills and of peer engagement in the mid-school years.

Count Us In—Growing Up with Down Syndrome. Jason Kingsley and Mitchell Levitz, 1994. (800.1 K55 1994).

This book presents conversations between two boys with Down syndrome discussing their life experiences growing up with Down syndrome and "share their innermost thoughts, feelings, hopes and dreams, and their lifelong friendship."

Differences in Common: Straight Talk on Mental Retardation, Down Syndrome, and Life. Marilyn Trainer, 1991. (226.11 T682 ECI).

A collection of essays tracing the growth of a little boy with Down syndrome into manhood, this book speaks to parents of a child who is "different." It is also valuable for the training of professionals who will help deliver early intervention services for infants and toddlers, and special education for older children. This book is a comprehensive description of parenting a child with Down syndrome.

Down Syndrome: A Promising Future, Together. Terry J. Hassold and David Patterson, 1999. (226.11 H355 1999 RHB).

This book attempts to summarize the highlights of the material presented during a four day national conference on Down syndrome, and should be of value to parents and relatives, expectant parents, and physicians, all of whom deal with individuals who have Down syndrome.

Down Syndrome: Birth to Adulthood: Giving Families an Edge. John E. Rynders and J. Margaret Horrobin, 1996. (226.11 R995 1996 ECI).

In this book, the authors share photographs and real life case studies of families from the EDGE Project at the University of Minnesota to guide parents of children with Down syndrome.

Down Syndrome: Living and Learning in the Community. Lynn Nadel and Donna Rosenthal, 1995. (226.11 N124 ECI).

This book, a tool for parents and health care professionals, contains an overview of medical advances, information about the programs and services available, and commentaries by young adults with Down syndrome who describe in their own words their feelings and accomplishments. The focus of this book addresses the challenges of people with Down syndrome as they become part of the community.

The Down Syndrome Nutrition Handbook: a Guide to Promoting Healthy Lifestyles. Joan E.G. Medlen, 2002. (226.11 M491 2002 ECI).

This book presents information on nutrition and healthy living for children with Down syndrome. It encourages parents to start teaching healthy habits early in their child's life but also stresses that it is never too late to begin healthy habits.

Down Syndrome - Books (continued)

Early Communication Skills for Children with Down Syndrome: A Guide for Parents and Professionals.

Libby Kumin, 2003. (226.11 K96 2003 ECI).

This book focuses on speech and language development from birth through the stage of making 3-word phrases. It contains the information parents need to ensure their child meets his/her communication potential, from an explanation of the speech-language assessment to descriptions of what to expect when a child enters school, and from new checklists on evaluating and treating speech problems to numerous home activities.

Early Education for Children with Down Syndrome. Valentine Dmitriev, 2001. (226.11 D628 2001 ECI).

This book is intended as a reference, textbook and a manual for parents, teachers, and other professionals who wish to accelerate the development of children with Down syndrome or with other developmental delays.

Fine Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals. Maryanne

Bruni, 1998. (226.11 B896f 1998 ECI).

This guide shows parents and professionals how they can help children with Down syndrome improve fine motor functioning from infancy to twelve years of age with appropriate intervention and practice.

Genetics and Mental Retardation Syndromes: A New Look at Behavior and Interventions. Elizabeth M.

Dykens, Robert M. Hodapp, and Brenda M. Finucane, 2000. (226.1 D996 2000 RHB).

This book presents a comprehensive guide to the genetic and behavior characteristics of nine specific genetic mental retardation syndromes explaining how they affect individuals' behavior.

Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals. Patricia C.

Winders, 1997. (226.11 W723 ECI).

Children with Down syndrome master gross motor skills — everything from rolling over to running — but need additional help and encouragement to maximize development. In this book, the author, a physical therapist, shares her expertise and experience. She provides parents and professionals with essential information about motor development including the impact of temperament and the effect of physical and medical conditions associated with Down syndrome.

Improving the Communication of People with Down Syndrome. Jon F. Miller, Mark Leddy, and Lewis A.

Leavitt, 1999. (226.11 M648i 1999 ECI).

This book provides a framework for assessing and treating speech, language, and communication problems in children and adults with Down syndrome.

Life As We Know It. Michael Berube, 1996. (226.11 B463 ECI).

This book tells the story of the first four years in the life of James Berube, who was born with Down syndrome, and the issues he faced at each stage in his development. These issues include I.Q. testing, the politics of education, disability law, social services, health care and entitlements. The author is James' father and his purpose in writing this book is to represent Jamie, and in so doing, to ask about our obligations to each other, individually and socially.

Medical and Surgical Care for Children with Down Syndrome: A Guide for Parents. D.C. Van Dyke, Philip

Mattheis, Susan Schoon Eberly, and Janet Williams, 1995. (226.11 V288 ECI).

This book, written by a team of twenty-five experts in the fields of medicine, dentistry, rehabilitation, psychology, nursing, and nutrition, gives parents an overview of specific medical conditions that are common among children with Down syndrome. These conditions include: heart disease, immune system concerns, endocrine conditions, eye conditions, skin conditions, ear, nose, and sinus conditions, gastrointestinal problems, orthopedic conditions, leukemia, dental concerns, reproductive issues, and neurological problems.

A Parent's Guide to Down Syndrome: Toward a Brighter Future. Siegfried M. Pueschel, 2001. (226.11 P977 2001 ECI).

This guide for new parents of a child diagnosed with Down syndrome, identifies what parents should expect as their child grows and what they can hope for in terms of health, schooling, and the child's life in the community. It is written by a well-known and well-respected doctor, who has given advice to parents for over ten years. This revised edition contains updated legislation and new developments in the biomedical field.

Down Syndrome - Books (continued)

Sindrome de Down y Educacion. Jesus Florez and Maria Victoria Troncoso, 1991. (226.11 F663 ECI).

In this book, written in Spanish, several experts in the field of education of children with Down syndrome share their ideas and present the current theories.

Teaching Reading to Children with Down Syndrome: A Guide for Parents and Teachers. Patricia Logan Oelwein, 1995. (226.11 Oe6 ECI).

Children with Down syndrome can be taught to read using an approach that provides for their unique learning styles and needs. This book describes a nationally known reading program that ensures success by presenting lessons which are both imaginative and functional and which can be tailored to meet the needs of each student.

Down Syndrome - Children's Books

Big Brother Dustin. Alden R. Carter, 1997. (805.1 C323 1997).

A boy with Down syndrome helps his parents and grandparents get ready for the birth of his baby sister and chooses the perfect name for her.

How About a Hug. Nan Holcomb. (805.1 H725h).

Though it takes much concentration and will for her to accomplish each task, a little girl with Down syndrome is happy to have many loving helpers along the way.

My Sister Annie. Bill Dodds. (805.2 D661).

This book presents the story of growing up, trying to be accepted, and having a sister with Down syndrome, which makes life a challenge for Charlie.

Russ and the Almost Perfect Day. Janet E. Rickert, 2000. (805.1 R539 2000).

Russ, a student with Down syndrome, is having a perfect day until he realizes that the five-dollar bill he has found probably belongs to a classmate.

Russ and the Apple Tree Surprise. Janet E. Rickert, 1999. (805.1 R539 1999).

After Russ, a five-year-old with Down syndrome, picks a basket of apples and helps his mother and grandmother bake a pie, his grandfather invites him into the backyard for a surprise.

Russ and the Firehouse. Janet E. Rickert, 2000. (805.1 R539 2000).

Russ, a five-year-old with Down syndrome, visits his uncle's firehouse and gets to help with the daily chores.

Where's Chimpy? Berniece Rabe, 1988. (805.1 R114 1988).

Text and photographs show Misty, a little girl with Down syndrome, and her father reviewing her day's activities in their search for her stuffed monkey.

Down Syndrome - Videos

Down Syndrome—A Parental Perspective. 20 minutes. (226.11 S741).

This video presents positive, real experiences and discussion by a group of parents of individuals with Down syndrome. Dr. W. Carl Cooley said, "Someone said that looking at a kid with Down syndrome is like looking at the stars, the more you look the more you see."

Down Syndrome—The First 18 Months. 108 minutes, 2003. (226.11 S326).

This video, which is organized around four parts: the newborn, health concerns, therapies, and new expectations, presents interviews throughout with nine international medical experts on Down syndrome and several parents of children with Down syndrome discussing their children.

Down Syndrome - Videos (continued)

Early Use of Total Communication—Parents' Perspectives on Using Sign Language with Young Children with Down Syndrome. 22 minutes, 1991. (226.11 G442).

To overcome the obstacle of slow communication development in children with Down syndrome many parents and professionals are using a total communication approach that combines speech with sign language. On this tape parents speak candidly about their initial fears as well as the benefits and drawbacks of using total communication with their child.

Graduating Peter—Down Syndrome in the Inclusive Classroom. 75 minutes, 1993. (557H765).

This documentary video features Peter's educational experiences in sixth grade, eighth grade and high school as he adds speech therapy and life skills classes and on-the-job training to his academic coursework. Interviews with Peter's parents, teachers, fellow students, aides, and doctors demonstrate the broad-based, ongoing support mobilized to help him fight depression, improve his ability to communicate, and move ahead in building a meaningful life for himself.

Journey of a Lifetime—Beginning with the End in Mind. 66 minutes. (800.1 G131).

In this video, Karen Gaffney presents her life growing up with Down syndrome by sharing how her parents, younger brother and doctors helped her to live as normal a life as possible. The comments are addressed to parents of an infant diagnosed with Down syndrome to let them know it won't be easy but is certainly worth the trouble and love they'll put forth.

The Kid Who Wouldn't Quit—The Brad Silverman Story. 29 minutes, 1984. (226.11 Si39).

This shows the remarkable achievements of a child born with Down syndrome, based on actual events. It dramatizes the faith and courage of a family that adapts to their son's disabling congenital condition. The video shows Brad and his parents as they overcome the challenge of regular public school and the stereotypes they encounter from teachers and other students.

Like Any Child—Raising a Child with Down Syndrome. 22 minutes, 1995. (226.11 Sh53).

It is far easier to see the similarities between a child with Down syndrome and his or her peers than it is to focus on the differences. In this video, parents who are expecting their first child who has been diagnosed with Down syndrome, relate their feelings and anticipation of the birth. Later interviews reveal that many of their worries have been unsubstantiated; they love their son and he is doing well.

Lily—A Sequel. 15 minutes, 1998. (800.1 G729).

This video tells the story of the author's daughter's life growing up with Down syndrome and shows the three years from her senior year in high school (age 20) through her first 2 1/2 years in a group home. Because of Lily's openness in discussing her situation, she gives insights to the full life possible for those with Down syndrome, and for their families.

Raymond's Portrait. 27 minutes, 1997. (800.1 H874).

This video presents the life of 19 year old Raymond Hu, a Chinese brush painter born with Down syndrome, through home movies and interviews with both parents, his brother, art teacher and Raymond himself. Raymond's sensitivity and passion for life comes out through his paintings of animals. He is featured in the June 1996 *Exceptional Parents'* 25th anniversary issue presenting 25 outstanding role models for the next 25 years.

Your Baby Has Down Syndrome. 27 minutes. (226.11 C536).

This video presents several families of babies with Down syndrome who share the emotions, both positive and negative that they experienced learning their baby had Down syndrome. It shows the joy and positive effects this child had on their lives. The parents of Mackenzie Sara Noca created this video project in her memory.

Down Syndrome - Selected Web Sites

The National Down Syndrome Society's mission is to benefit people with Down syndrome and their families through national leadership in education, research and advocacy. This website is immense and attempts to be the comprehensive information source on Down syndrome. See <http://www.ndss.org>

"Facts about Down Syndrome" from The National Institute of Child Health and Human Development (includes a list of organizations that can provide more assistance):

<http://www.nichd.nih.gov/publications/pubs/downsyndrome/down.htm>

More links to information and resources about Down syndrome are available at MedlinePlus, a website provided by the National Library of Medicine. See <http://www.nlm.nih.gov/medlineplus/downsyndrome.html>

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Early Childhood Report - May 2005

Early CHILDHOOD Report

Volume 16, Issue 5 May 2005

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An online screening can help you detect reading difficulties in young learners before they fail.

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Colorado developed school readiness indicators so they can learn where they need to concentrate efforts and resources. Learn how they did it and what they have planned for the future.

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A recent study found that training fathers to communicate and play with their young autistic children improves the children's development and helps dads take more active roles. Learn how and what researchers have planned next.

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