

Recommended Books About the Disability Experience

Adventures in the Mainstream: Coming of Age with Down Syndrome. (2005). Greg Palmer. Like many parents, Greg Palmer worries about his son's future. But his son Ned's last year of high school raises concerns and anxieties for him that most parents don't experience. Ned has Down syndrome; when high school ends for him, school is out forever. The questions loom: What's next? How will Ned negotiate the world without the structure of school? Will he find a rewarding job in something other than food service? To help him sort out these questions and document his son's transition from high school to work, Palmer, an award-winning writer and producer of PBS documentaries, keeps a journal that's the basis of this thoughtful and entertaining book. (Amazon.com)

After the Tears: Parents Talk About Raising a Child With a Disability. (1987). Robin Simons. In parenting a child with a disability you face a major choice. You can believe that your child's condition is a death blow to everything you've dreamed and worked toward until now or you can decide that you will continue to lead the life you'd planned - and incorporate your child into it. Parents who choose the latter course find they do a tremendous amount of growing. This is the story of many such parents - parents who have struggled, learned and grown in the years since their children were born. They share their stories with you to give you the benefit of their experiences, to let you know you're not alone, and to offer you encouragement in growing with and loving your child. (Wyoming Parent Information Center)

Aidan's Way: The Story of a Boy's Life and a Father's Journey. (2004). George T. Crane An Asian studies professor at Williams College, Crane mines his academic field to tell the story of his profoundly disabled son's life, unpacking a grab-bag of Asian philosophy and its relationship to his son's humanity and worth. Crane's thesis that "disabled people are not marginal to the human experience; they are central to it, for without them there could be no definition of ability," while not novel, is a stimulating addition to the public debate over the rights of the disabled. Crane's son, Aidan, has had seizures since he was 10 days old, and at age seven he "still could not walk or talk or see. His abilities were closer to those of a three-month-old infant." The author recounts the many years of doctor visits and the frustrations and triumphs he and his wife experience as they attempt to give their child meaningful care. Publishers Weekly.

As We Grew Up with Barbara . (1980). Lotte Moise. A common sense book and personal account by a mother of her daughter's growth and their adult relationship. (Cypress House)

Autobiography of a Face. (1994). Lucy Grealy. *Autobiography Of A Face* is Lucy Grealy's compelling account of her experience with childhood cancer. The narrative's starting point of view is that of Grealy as a child, from her early diagnosis at age nine, replete with the singular distinction of being sick and thus being special and not having to turn in a book report, through surgery that removed half of her jaw, almost three years of radiation and chemotherapy, to her growing awareness that she is alone and experientially set apart from her family, her classmates, and her physicians. The book chronicles her hospital and school experiences as well as her internal struggle to eschew the mirrors that reflect difference, what she gradually realizes is, by society's standards, her "ugliness" or to embrace the mirrors that reflect liberation from image and instead reflect the face of the self.

All by Self. (1991). Ron Taylor. Describes the author's first six years of adventures with his son Micah who has CP and significant challenges. It is beautifully illustrated in pencil/paper and some color drawings by both Micah and his brother Jonah. The book was revised in 1995 with an additional story, fiction but full of insight, about Micah, his brother and mother taking a trip to a healing hot springs for a week.

Barbara and Fred, Grownups Now. (1998). Lotte Moise. Living fully with a disability is the theme of this mother's book about her daughter growing up. It is the sequel to As We Grew Up With Barbara.

Beyond Ramps: Disability at the End of the Social Contract: A Warning from an Uppity Crip. (1998). *Marta Russell*. An award-winning producer and photographer whose investigative reporting earned her a Golden Mike Award for best documentary from Radio & Television News Association of Southern California in 1994, Russell delivers a vividly written, lucid analysis of the social safety net and its failure to cover people with disabilities and their families — Marcus Raskin, co-founder, Institute for Policy Studies, Professor of Public Policy, George Washington University

Beyond the Silence: My Life, the World and Autism. (2000). Mukhopadhyay, T. R. London: The National Autistic Society. This work is an autobiographical narration of a young poet who has autism and it includes a collection of his selected poems with a foreword by Lorna Wing. Rajarshi Mukhopadhyay, known as Tito, wrote this fascinating narration before he was 12 years old. This work represents a realistic presentation of what kind of struggle he and his parents had to go through during his early childhood in his native country (India) where intellectual disabilities like autism are hardly known or recognized. The initial two sections present Tito's autobiographical narration while the remaining two sections present a collection of his selected poems.

Body, remember. (1997). Fries, K. New York: Plume. In this memoir, Kenny Fries explores his life and experiences with his disability. Having been born with congenital deformities that affected the lower part of his body, Fries searches medical records, talks with family and friends, and examines past relationships in order to better understand his disability. In addition to an understanding of his physical body, Fries also explores his sexuality and personal relationships. This is a memoir about disability, but it is also about the discovery and understanding of his identity.

The Body Silent: An Anthropologist Embarks on the Most Challenging Journey of his Life: Into the World of the Disabled. Murphy, R. F. (1987). London and New York: W.W. Norton. Robert Murphy, an anthropologist by trade, eloquently and honestly describes how paralysis--and all disability--affects identity and interaction with others based on their reactions to disability. This book is his anthropological field trip to the world of disability, detailing his experiences and thoughts before, during, and after he becomes paralyzed during his 40s. This is a powerful book in which Murphy not only shares his personal story but deals with and challenges the ableism and medical model of disability he endures once he becomes disabled himself.

The Broken Cord. (1990). Michael Dorris. When Michael Dorris, 26, single, working on his doctorate, and part Indian himself, applied to adopt an Indian child, his request was speedily granted. He knew that his new three-year-old son, Adam, was badly developmentally disabled; but he believed in the power of nurture and love. This is the heartrending story, full of compassion and rage, of how his son grew up mentally retarded, a victim of Fetal Alcohol Syndrome whom no amount of love could make whole. The volume includes a short account of his own life by the 20-

year-old Adam, and a foreword by Dorris' wife, the writer Louise Erdrich. *The Broken Cord* won a National Book Critics Circle Award in 1989.

Changed by a Child. (1997). Barbara Gill. This is a book of meditations for parents of children with disabilities. Many parents have said that they use this as a centerpiece in discussions, and give copies to new parents they meet. Raising a child with a disability can often be more isolating and frustrating than any parent ever imagines. Finally, here is a book that honestly describes the inner needs and range of issues parents with disabled children face. *Changed by a Child* invites parents to take a moment for themselves. Each of the brief readings offers comfort and hope as they capture the unique challenges and joys of raising a disabled child. (Random House)

A Child Called Noah. (1989). Josh Greenfeld. The joy and hope with which Greenfeld recorded Noah's birth in his journal were not to last. By the age of two and a half, Noah had stopped talking, had difficulty performing the simplest tasks, and could not communicate with his parents. The doctors consulted by the Greenfelds were as baffled as Noah's beleaguered parents. Vacillating between hope and despair, and increasingly aware of the impact caring for a child like Noah would have on their lives, the anguished Greenfeld family journeyed from New York to Connecticut to California in search of help. An honest, harrowing, and profoundly human story. (Wyoming Parent Information Center)

The Child Who Never Grew. (1992). Pearl S. Buck. "...Buck turned away from fiction for this heartfelt 1950 volume about her mentally retarded daughter. The volume broke the taboo against raising the subject [of mental retardation] in public and laid the groundwork for the literature on the disabled that followed." -*Library Journal*

Choosing Naia: A Family's Journey. (2003). Mitchell Zuckoff. For a 1998 Boston Globe article, reporter Zuckoff interviewed Greg and Tierney Fairchild, a happily married, interracial professional couple who went for the usual prenatal screenings and came away knowing that the fetus carried a major heart defect that could signal Down syndrome. Up against Connecticut's 24-week deadline for elective abortions, the couple struggles with complicated ethical and practical concerns, since the newborn would have to undergo major open-heart surgery and face lifelong disabilities. In the end, they decide this will simply be one more challenge they'll face together. *Cahners Bus. Inf.*

Count Us In: Growing Up with Down Syndrome. (1994). Jason Kingsley & Mitchell Levitz - Kingsley and Levitz write about education, employment, ambitions, families, sex and marriage, and their disability -- Down Syndrome. At Jason's birth, the obstetrician said that he'd never learn anything and should be institutionalized. Fortunately, the Kingsleys ignored this advice, and their son has since attended school, written poetry, registered to vote, and memorized scripts for appearances on "Sesame Street" and "The Fall Guy." Hearing about Down syndrome directly from these young men has a good deal more impact than reading any guide from a professional or even a parent. Their comments are eye-opening and heartening. (Booklist).

Cushla and Her Books. (1980) Dorothy Butler Cushla and her books is a heartwarming story of two parents who are devoted to raising their daughter with significant disabilities. Even though these disabilities stunted her physical and cognitive development, her parents were determined to give Cushla the best quality of life. Cushla's mother introduced books to her at a young age and read to her on a continual basis. As Cushla aged, the constant exposure to books increased her cognitive development began to recognize words and pictures, and simply developed a love for books. However, several aspects of the story were presented in a textbook manner that made the reading often tedious and disengaging. Overall, the book has a strong message and is very informative (Amazon)

Dazed and Fatigued in the Toxic 21st Century (1998). Mark Llewellyn Hallan astonishing first person experience in recovering from chronic fatigue syndrome. Written in an alternative voice that is raw and at times wildly spontaneous, the story weaves poetry with ironic insights and commentaries. ... Amazon.com

A Difference in the Family. (1981). Helen Featherstone. In this wise, compassionate account, Helen Featherstone, educator and mother of a severely disabled child, traces the long, often heartbreaking road toward complete acceptance of disability. Drawing on interviews with parents and professionals, published accounts, and her own personal experience, she discusses how parents and siblings cope with their feelings of fear, anger, guilt, and loneliness. (Wyoming Parent Information Center)

Differences in Common Straight Talk on Mental Retardation, Down Syndrome, and Life. (1991) Marilyn Trainer. This collection of engaging essays goes a long way toward improving understanding of the effects and potential of Down Syndrome. Trainer, mother of a young adult with Down Syndrome and activist for the rights of the disabled, writes with perception and eloquence on the many issues which families of children with Down Syndrome must face: public attitudes, family adjustment, education, mainstreaming, adolescence, and independence. Particularly compelling is her report of the employment situation facing mentally retarded adults. Trainer makes a strong case for the worthwhile accomplishments which can be realized through the combination of a supportive family, funds for training, and a willing community. (Library Journal)

A Different Kind of Boy: A Father's Memoir About Raising a Gifted Child with Autism. (2001). Dan Mont. A little nine-year old boy looks down at the gymnasium floor. The room is filled with children who like and respect him, but he has no real friends. He can barely name anyone in his class, and has trouble with the simplest things - recognizing people, pretending, and knowing when people are happy or angry or sad. Much of his life has been filled with anxiety. And yet he was only one of seven fourth graders in the United States to ace the National Math Olympiad. In fifth grade he finished second in a national math talent search. That boy is autistic. He is also loving, brilliant and resilient. In this book, his father writes about the joys, fears, frustration, exhilaration, and exhaustion involved in raising his son. He writes about the impact on his family, the travails of navigating the educational system, and the lessons he has learned about life, what it means to connect with other people, and how one builds a life that suits oneself. And, oh, yes, math. Lots about math. (Jessica Kingsley, Publisher)

Does She Know She's There? (2000), Nicola Schaefer, with candor, poignancy and humor, Schaefer chronicles her steadfast determination not to institutionalize or stigmatize her daughter. Readers may be moved to tears and laughter as they share the tragedies and triumphs of these two unique women. Due to the challenges faced by Catherine, stories of even the most ordinary events in her life become extraordinary. This a celebration of the lives of some remarkable people; in that respect, it succeeds admirably." - Canadian Book Review Annual

Don't Pull the Plug: A Lesson in Life. (2002). Thomas Matola and Roberta Johnson. Matola was a teacher, a hiker, a dancer. Then at age 61, he suffered a major stroke. Shut off from the world, from almost all communication, from his joys and his livelihood, he felt anger, frustration and despair. When his doctor asked him if he wanted to have the plug pulled, he thought about the life he had, and the life he could look forward to. And he decided to live; to learn to live a new life — a fulfilling life, full of love and growth, and a determination to improve physically, mentally and spiritually. (Disabilities Books)

Don't Worry, He Won't Get Far on Foot. (1989). John Callahan. Equal parts laugh-out-loud funny and angering to the point of disbelief, this is John Callahan's story told in his own words and pictures. John is a cartoonist whose work not only challenges but attacks and explodes social norms. He is also a quadriplegic and recovering alcoholic who has suffered through abusive support providers, endured battles with the welfare system, maintained his vicious sense of humor, and emerged from some difficult times happy, successful, and determined to change prevailing attitudes about disability, potential, normalcy, and employment. He shares all of his experiences and lessons learned in a straightforward way that does not allow pity or ego to enter the picture. He describes his own brand of faith and sheds some light on our collective humanity.

Emergence Labeled Autistic (1996). Temple Grandin. Grandin was diagnosed with autism at the age of three. An intelligent child with a thirst for knowledge, but unable to properly express herself or control her behavior, Temple struggled through grade school. Eventually moved from a 'normal' school to an educational program for autistic children, she began to suffer 'nerve attacks.' Now Temple tells the story of how she went from a fear-gripped child to a successful professional and a world leader in her field. A chronicle of perseverance and courage, EMERGENCE gives new hope and insight into the tragedy of autism and the vast potential of the human spirit. (Amazon)

Exile & Pride (1999). Eli Claire. Eli Clare, a poet with cerebral palsy, movingly describes her attempt to climb Mount Adams -- not, she points out, as a "supercrip," but just as an impaired person who loves to hike: a story about ableism rather than disability. Avoiding easy answers and journalistic sunshine, she recounts the story of the fight for disabled access. "I think of the words *crip, queer, freak, redneck,*" Clare remarks. "None of these are easy words. They mark the jagged edge between self-hatred and pride, the chasm between how the dominant culture views marginalized peoples and how we view ourselves, the razor between finding home, finding our bodies, and living in exile, living on the metaphoric mountain." --*Regina Marler*

Expecting Adam, A True Story of Birth, Rebirth, and Everyday Magic. (2000). Martha Beck. An autobiographical tale of an academically oriented Harvard couple who conceive a baby with Down's syndrome and decide to carry him to term. Despite everything Martha Beck and her husband John know about themselves and their belief system, when Martha gets accidentally pregnant and the fetus is discovered to have Down's syndrome, the Becks find they cannot even consider abortion. The presence of the fetus that they each, privately, believe is a familiar being named Adam is too strong. As Martha's terribly difficult pregnancy progresses, odd coincidences and paranormal experiences begin to occur for both Martha and John, though for months they don't share them with each other. Martha's pregnancy and Adam become the catalyst for tremendous life changes for the Becks.

Faking It: A look Into the Mind of a Creative Learner. (1992). Lee, C. & Jackson, R. The author provides those of us who do not have learning disabilities a view into his world and the perspective from which he approaches life and learning. As a teacher of students with learning disabilities, this book has helped me to approach my students in a different and... better way. I routinely recommend this book to other teachers and parents, so that understanding and acceptance can be cultured. I applaud the author for taking the bold step to share relevant information with those of us who work with individuals with learning disabilities (an Amazon Reader)

Fighting for Darla: Challenges for Family Care and Professional Responsibility : The Case Study of a Pregnant Adolescent With Autism (1994). Ellen Brantlinger, Susan Klein and Samuel Guskin. The authors say, "Often the professional literature implies that a consensus exists

regarding meeting needs and delivering services to people with disabilities. On the contrary, our research has led us to the strong conviction that tentativeness, anxiety, and misgivings often surround the actions of those providing care and well as those who receive care. Darla reminds us that the real world is complicated and never easy; she forces us to struggle with our own sense of helplessness and despair when the real world does not live up to our expectations. Although she has not language that we can understand, Darla teaches us...." OAARSN Book Review

Finally, Dreams Coming True. (2006). Jacqueline Speciner. This is a book with a twofold purpose. It is a memoir about the life, challenges, and accomplishments of Jacquie, a woman with cerebral palsy. It is also a resource for people with disabilities who want to live independently.

From the Heart: On Being the Mother of a Child With Special Needs. (1995). Jayne Marsh. Nine mothers explore the intense, sometimes painful, emotional terrain of raising children with special needs in eye-opening narratives developed from their parent support group meetings. The children who shape these women's lives have disabilities that include autism, Down Syndrome, Tourette syndrome, and ADD. These mothers affirm the experience of other parents like themselves. From the Heart speaks to anyone who may know little about raising a child with special needs -- until they have one and must then forge a strong family unit nonetheless. (Midwest Book Review)

I Don't Want To Be Inside Me Anymore: Messages from an Autistic Mind, (1995). Birger Sellin. Sellin is a 21-year-old autistic German who has written a slender volume of epigrammatic musings using the technique of facilitated communication (FC), a method whereby the autistic person types messages, one letter at a time, with one finger, using a "facilitator" to support the elbow or arm. Library Journal.

I Had No Means to Shout. (1999). Charles Hale. Hale, a man with autism, discovered the communication technique of facilitated communication (FC) when he was 36 years old, and this book chronicles his life before and after he began to use FC. The narrative provides, in Charles' voice, a fascinating and detailed insiders' perspective to what autism feels like, how Charles' apraxia and dyspraxia have affected his life and his communication, and how FC allows Charles not to emerge from autism, but rather, to express himself "as the intelligent, cognizant man he really is."

I Raise My Eyes to Say Yes. (1989). Ruth Sienkiewicz-Mercer. A powerful account, written with the assistance of Steven Kaplan, of Sienkiewicz-Mercer's incarceration in an institution for people labeled mentally retarded. She vividly describes the abuse and neglect she experienced in the institution, and the isolation from family and community. However, the book ends with her description of her successful struggle to gain her freedom, shatter stereotypes, and build a life in the community.

If Your Dreams Are Big Enough, The Facts Don't Count. (1990). Michael S. Long. The author is a wise man and does not recall his past in order to place blame but to open the eyes of educators today to the desperate importance of their roles. Written from the perspective, and in the actual words, of a person with a developmental disability...a "must" read.

Incurably Human. (2000). Micheline Mason. Simultaneously personal and philosophical, this book is both a celebration of and call for inclusive communities and schools. Micheline Mason shares some of her experiences growing up and living with a disability in London. She challenges the dominant ideology of the medical model that suggests that she and others with disabilities are broken and need to be fixed, stressing that she is fully human as she is and does not need or

desire a cure. The book chronicles her personal journey from experiencing segregation and discrimination to living a full life, fighting prejudice, and working for inclusive societies.

Life as We Know It: A Father, Family, and an Exceptional Child. (1998). Michael Berube. This remarkable book is a father's story of the life of his 4-year-old son James, who has Down syndrome. It is far more than just a personal memoir of his son's birth and young life. In following the developmental stages, social experiences, and involvement with social services that James passes through, Bérubé explores their social implications, including such topics as IQ testing, the politics of education, disability law, social services, health care, and entitlements. Implicit in these discussions are not just his own family's experiences in these realms, but also concepts such as social justice, what it means to be human, and what kind of society is valued and by what means we determine this value.

Like Colors to the Blind. (1996). Donna Williams. This is Donna Williams' third book about her life as a person with autism. When she was diagnosed with autism at the age of 25, she wrote *Nobody, Nowhere* as an attempt to explore her experiences as a person with autistic symptoms. In her sequel, *Somebody, Somewhere*, she continued to analyze how role-playing and ritualistic behavior helped her to cope with her environment, and how she was able to begin to replace these mechanisms with genuine interactions. This, her latest work, builds upon the last, addressing relationships and emotions. Williams describes her relationship with Ian, who became her best friend and eventually her husband.

Lost in a Desert World: The Autobiography of Roland Johnson. (1999). Roland Johnson and Karl Williams. Forty or fifty years ago, when a child was born with a developmental disability - mental retardation, in Roland Johnson's case - the doctor would invariably counsel the parents to put their son or daughter away and forget about them. Roland Johnson's mother and father did not take this advice. But in the 1950s in Philadelphia they had no one to help them - no counselors, no psychologists, no therapists, no teachers. And when the problems that Roland's disability presented began to overwhelm them, they had no choice but to resign themselves to that original advice. Roland Johnson spent half his childhood at Pennhurst State School outside Philadelphia, where he saw fellow residents abused and where he himself was abused. But somehow he was able to keep his spirit alive. When he won his freedom as a young adult, he spent several years putting his life together. Then, as president of Speaking For Ourselves, he became an internationally known speaker and leader in the self-advocacy movement. (Amazon)

Lucy's Story: Autism and Other Adventures. (1999). Lucy Blackman. In her autobiography, Lucy Blackman gives a very detailed insider's view of autism before and after she learned to communicate through typing. This book, as well as being a fascinating autobiographical narrative, is essential reading on the aspects of sensory discrimination, issues of visual perception, and discussion of the rituals associated with autism. Blackman also provides an in depth discussion of her school placements, what worked, what did not work in her school settings, and how her family relationships bridged both her school and communication gaps. A majority of the book provides a comprehensive discussion of the method of facilitated communication (FC).

The Me in the Mirror.. (1994). Connie Panzarino Written by writer, disability activist, and artist Connie Panzarino, *The Me In The Mirror* is an autobiography of the life of this amazing woman. Born with Spinal Muscular Atrophy Type III, a rare disease, Panzarino describes her life as one of struggles and triumphs, and tells the stories of her relationships with her family, friends, lovers, her turn to lesbianism, and of her years of pioneering work in the disability rights movement. This book is a must read for anyone interested in understanding the experiences of women with physical disabilities.

Meditations from A Movable Chair: Essays (1998). Andre Dubusthe twenty-five pieces in this powerfully moving new collection [are] a continuation of Dubus's candid, intensely personal exploration into matters of morality, religion and creativity. ... Here is Dubus on the rape of his beloved sister, his first real job, a gay naval officer, Hemingway, the blessing of his first marriage, his dear friend Richard Yates, his own crippling, lost autumnal pleasures, ... the Catholic church and, of course, his faith." (The Council on Disability Rights)

Movie Stars and Sensuous Scars, Essays on the Journey from Disability Shame to Disability Pride. (2003). Steven E. Brown. Chronicles the author's journey from disability shame to disability pride — and then some. Includes a too-brief biography of his friends, Ed Roberts and Ed's mom, Zona (what a woman!); the story of how Kalamazoo, Michigan got America's first curb cuts in 1945; a tale of first CIL to wrest control from a bad board; the best work we've seen on the reality of pain in his chapter "Hooked on Symptoms"; "The Truth about Telethons" and altogether more surprising and beautiful work than we can describe here. Just get it." --Mouth Magazine

Moving Violations: War Zones, Wheelchairs, and Declarations of Independence. (1995). John Hockenberry. *Moving Violations* is an honest and often humorous account of Hockenberry's life as a man with a disability. He takes the reader on a journey in which he reflects upon the events in his life, from the accident that, at age 19, caused a spinal cord injury, to his work as a nationally renown broadcast journalist. He does not flinch at talking about the personal aspects of disability. And he shares the adventures of his career, such as riding a mule up a mountainside with Kurdish refugees who were being driven from their land by the Iraqis after Desert Storm. Hockenberry also explains how his disability, rather than limiting him, is a window through which he frames his view of the world--how it expands his gaze and gives him insight that defines who he is and what he does.

My Body Politic. (2005), Simi Linton In this volume, Linton recounts her personal odyssey, from flower child "walkie" in 1971 to disability-rights/human rights advocate in 2005. A car accident en route to a Vietnam War protest took the lives of Linton's husband and her best friend, and left Linton in a wheelchair. In the '70s, this meant almost a year in hospitals and rehab facilities before being released to cope with Manhattan before the Americans with Disabilities Act—no cut-throughs on street curbs, unusable public transportation, rarely accessible bathrooms in public buildings and inaccessible rooms in most schools and workplaces. Linton managed, as others have, but it wasn't until she went to the West Coast and discovered the growing disability rights community that she began to see her situation in a political light. Reed Business Information, a division of Reed Elsevier Inc.

My Left Foot. (1954) Christy Brown. My Left Foot tells of the childhood and adolescence of Christy Brown, the author. Though Brown is born with severe cerebral palsy, unable to communicate or control his movements, his mother believes that his mind is unaffected. Her confidence in Brown's growing abilities never falters as her son grows up and becomes increasingly aware of his physical disabilities. BookRags.

Nobody, Nowhere: The Extraordinary Autobiography of an Autistic. (1992). Donna Williams. Donna Williams, who was diagnosed with autism when in her mid 20s, wrote *Nobody, Nowhere* in an attempt to understand herself and to explore how she fit into the world around her. She candidly describes the teasing and mistreatment she experienced at the hands of her family and her ability to use role-playing to interact with others. Williams said of her book, "This is a story of two battles, a battle to keep out 'the world' and a battle to join it. I have, throughout my private war, been a she, a you, a Donna, and finally, an I."

Nothing About Us Without Us: Disability Oppression and Empowerment (1998). James Charlton. "Jim Charlton, in a deeply moving work, demolishes old myths about disabilities. He reveals in stunning oral histories, conducted in ten different countries, possibilities yet untapped." — Studs Terkel. A defining document in the literature of disability culture. Jim Charlton chronicles both the history and experience of exclusion so familiar to people with disabilities. But he does it all in a style and with sensitivity that connects the voices of a unique community to the universal narrative of human rights. This is oral history and political manifesto rich with wisdom and insight on every page." — John Hockenberry (author of *Moving Violations*)

Parents Speak Out: Growing with a Handicapped Child. (1979). Ann and Rud Turnbull. Parents of children with disabilities discuss their experience and lives from a number of perspectives.

Planet of the Blind: A Memoir . (1998). Stephen Kuusisto. A beautifully written account that graces the reader with painful insight and self-revelation." — Jo Holzer, CDR Executive Director "Born with only residual vision, Kuusisto was led by the insistence of his mother and the ignorance of the society around him to an elaborate and harrowing attempt to appear sighted. ...the story of a lifelong struggle that leads to acceptance." — John Longenbaugh

The Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of The Disability Rag (1994). Barrett Shaw (ed.). Reading *The Ragged Edge* anthology is like sitting in on a vigorous, sometimes funny, and often irreverent roundtable discussion of the issues that most concern all humanity, disabled and nondisabled, whether they admit it or not. Some of the voices are reflective, some sad, some furious, but none will lull you to sleep. On the contrary, you'll feel ready to roll on out and transform the world. -- Nancy Mairs

Reflections from a Different Journey: What Adults with Disabilities Want All Parents to Know. (2005). Stanley D. Klein and John D. Kemp (eds.) Most parents of children with disabilities lack personal experience with adults with disabilities. Hearing from people who have lived the disability experience can provide all parents with essential information about the possibilities for their children. *Reflections from a Different Journey* includes forty inspiring and realistic essays written by successful adult role models who share what it is like to have grown up with a disability. Disabilities Books.

Riding the Bus with My Sister. (2003). Rachel Simon. This perceptive, uplifting chronicle shows how much Simon, a creative writing professor at Bryn Mawr College, had to learn from her mentally retarded sister, Beth, about life, love and happiness. Beth lives independently and is in a long-term romantic relationship, but perhaps the most surprising thing about her, certainly to her (mostly) supportive family, is how she spends her days riding buses. Rachel joined Beth on her rides for a year, a few days every two weeks, in an attempt to mend their distanced relationship and gain some insight into Beth's daily life. She wound up learning a great deal about herself and how narrowly she'd been seeing the world. Rachel juxtaposes this with the story of their childhood, including the dissolution of their parents' marriage and the devastating abandonment by their mother, the effect of which is tied poignantly to the sisters' present relationship. Although she is honest about the frustrations of relating to her stubborn sister, Rachel comes to a new appreciation of her, and it is a pleasure for readers to share in that discovery. (Publishers Weekly)

Secret Girl. (2006). Molly Bruce Jacobs. Imagine being 13 years old and discovering you have a younger sister secreted away in an institution. For Jacobs, the implications of her family's utter rejection of this sibling, diagnosed with hydrocephalus and labeled mentally retarded at birth, are

not fully revealed until she reaches adulthood and survives her own battles with alcoholism and an unsuccessful marriage. When she finally deems herself ready to come face-to-face with the sister she's never seen, Jacobs unearths a shocking portrait of abandonment and denial, exposing parents who were woefully ill equipped to handle imperfection in either of their daughters. For her part, Jacobs admits to being a conflicted sibling. As an adult, a guilt-driven Jacobs tries to compensate for those years of neglect by integrating Anne into her own unsettled lifestyle. With disarming candor, Jacobs creates a graphic account of one family's physical loss and one woman's emotional gain. American Library Association.

The Social Meaning of Mental Retardation: Two Life Stories, (1994). by Bob Bogdan and Steve Taylor. This was an amazingly powerful story written in first person. To understand the meaning of social retardation, read these life stories. they put an interesting and sad perspective on the manner in which they are dehumanized for being who they are. I would recommend this book for anyone who is going to be teaching or around these wonderful individuals. Adam Wilson.

Somebody Somewhere: Breaking Free from the World of Autism (1994). Donna Williams
The author continues the incredible story of her battle with autism begun in her first book, *Nobody Nowhere*. Here she offers more revelations about the mind of an autistic person and the role that emotions play in our inner lives."...one of those books that opens your mind. ... — Amazon.com

Son Rise. (1976). Barry Kaufman. In a world where parents of special-needs children are constantly told they don't know what's best for their children and the "experts" favorite answer is to forcefully "modify" a child's behavior to appear normal, this book is a refreshing demonstration of the power of parental love and determination. When told by the recognized experts that their son, Raun, was hopelessly autistic and mentally retarded, uneducable and in need of institutionalization, the Kaufmans chose to look to their child as his own expert. Hours of open-minded observation, experimenting and lovingly joining Raun's actions, gave them a unique understanding of him and the key to reach into his strange world and ultimately inspire him to become a part of theirs. Raun's total recovery from a supposedly incurable disorder is a demonstration that the "experts" don't always know best and that scientific studies often fall short. an Amazon reader.

Songs of the Gorilla Nation - My Journey Through Autism. (2004). Dawn Prince-Hughes. This memoir tells how Prince-Hughes learned to manage her form of autism, Asperger's syndrome, by observing and interacting with gorillas. The author's accounts of her early childhood are intensely moving as she describes how she viewed her world and how she tried to deal with it. What makes this book unique is the author's discovery of the gorillas at Seattle's Woodland Park Zoo, and how she learned about personal relationships, the need for companionship, and the need for a group to belong to by watching them. Though she dropped out of school at 16, wanting to learn more about the gorillas helped her to find a focus and led to an eventual Ph.D. in anthropology. American Library Association.

The Spirit Catches You and You Fall Down. (1998). Anne Fadiman. Lia Lee was born in 1981 to a family of recent Hmong immigrants, and soon developed symptoms of epilepsy. By 1988 she was living at home but was brain dead after a tragic cycle of misunderstanding, overmedication, and culture clash: "What the doctors viewed as clinical efficiency the Hmong viewed as frosty arrogance." *The Spirit Catches You and You Fall Down* is a tragedy of Shakespearean dimensions.

The State Boys Rebellion. About the boys deposited at Fernald. Fascinating. Excellent read. Tragic story. Looks at how a system skews peoples lives and then responds or doesn't. I'm pleased to say that Commissioner Morrissey took matters into his own hands before Fred Boysce died and responded to Fred at least in part, telling Fred in writing that Fred was not a "moron." This was important to Fred. The history of eugenics is in this book as well. It's a great read. I couldn't put it down. Cynthia Levine.

Sticks and Stones, by Elizabeth Pieper. A very powerful and beautifully written story of Betty's son Jeff's first five years, and perhaps partly because Betty was a very early adopter of the principle of normalization, it does not feel out of date. I have given copies to scores of families and staff over the years, and I still use one story from the book in my regular staff training classes. Jack Yates.

Thinking in Pictures: And Other Reports from My Life. (1995). Temple Grandin. *Thinking In Pictures* is about the childhood and development of Temple Grandin, a woman with autism. She likens herself to the robotic character, Data, on the science fiction television program, *Star Trek: The Next Generation*. She says words are like a second language to her, noting that she thinks primarily in images. Grandin, who holds a Ph.D. in animal science and has designed equipment that revolutionized the livestock industry, proposes that genius and autism may sometimes be closely related.

Too Late to Die Young: Nearly True Tales from a Life. (2006). Harriet McBride Johnson. It's hard to believe that one Charleston, S.C., woman, from the seat of her wheelchair, has faced off President Reagan's Secret Service detail, disrupted a National Democratic convention, joined disability advocates in Cuba and—for 13 years straight—protested the Jerry Lewis muscular dystrophy telethon. Johnson, who was born with a congenital neuromuscular disease, wants kids with disabilities to grow up "prepared to survive," not merely waiting to die. Equally problematic for the spirited lawyer are media heroes like the late Christopher Reeve, who revived "telethon melodrama" by displaying himself as "a disability object, presumably tragic but brave, someone to gawk at." Johnson, whose law practice specializes in disability advocacy, has a personal assistant, a motorized wheelchair and a supportive circle of family and friends that make her active, satisfying life possible. Reed Business Information

Under the Eye of the Clock. (1987). Christopher Nolan. Christopher Nolan is an award-winning Irish poet and novelist who has cerebral palsy, uses a wheelchair, and writes with a stick attached to his forehead while someone cups his chin for stability. *Under the Eye of the Clock* is his autobiography (told as the story of Joseph Meehan), a lyrical and metaphorical account of his family, schooling, faith, and emergence as a celebrated poet. Joseph communicates with eye movements, facial expressions, and body language that his family and friends decode, and Joseph used his language to tell his family and teachers at the Central Remedial Clinic School that he wanted to attend the local comprehensive school. While his family is completely supportive and respects Joseph's autonomy, the board repeatedly turns down Joseph's application, but Joseph eventually is accepted at the comprehensive school and finishes his primary education there.

Waist-high in the world: A Life among the Disabled. (1997). Nancy Mairs. Mairs, a brilliant essayist and poet who has authored six previous books, reflects upon her experiences as a woman with multiple sclerosis. She discusses such topics as adjusting to change, reconciling body image, experiencing sexuality, and seeking equality and justice. She also probes other disability issues, such as assisted suicide and selective abortion, and she revisits an article she once wrote for *Glamour* magazine that focused on young people with disabilities.

Where is the Mango Princess? (1991). Cathy Crimmins. Although it was frightening when Crimmins's husband, Alan, an attorney, suffered a traumatic brain injury (TBI) while on a family vacation, it was his long-term rehabilitation that proved most daunting, for brain injuries can cause significant personality changes. This chronicle of Al's injury, treatment and rehabilitation shows how perplexing and stressful traumatic brain injury can be for both victim and family. Reed Business Information,

What Happened to You: Writing by Disabled Women. (1996) Disabled women face even greater obstacles than do women generally, and physically challenged lesbians and women of color deal with yet another set of problems. This anthology of prose, poetry, fiction, and personal memoirs by 36 disabled British women provides an interesting view of their life experiences. Full of anger, pain, rage, hope, warmth, humor, and politics, their work shows readers daily life with its struggles, failures, and triumphs. Barbara M. Bibel,

What's that pig outdoors?: A Memoir of Deafness. (1990). Henry Kisor. Kisor, book editor of the Chicago Sun-Times, lost his hearing after a bout with meningitis at age three and has since relied on spoken language and lip reading. Genial and moving, sharp and witty. With unflinching candor and telling details, Kisor cites the ways in which being deaf among the hearing shaped his personal and professional experiences. Pub. Weekly

Women with Disabilities: Found Voices. (1994). Mary Willmuth and Lillian Holcomb, eds. This is a deeply personal and compelling discourse of the body, violence, sexuality, and disability. The authors offer a multicultural perspective, which speaks frankly about their experiences. They discuss the abuses they have endured and explain how they have struggled with the issue of being a woman with a body that does not conform to the image that society values.

A World Without Words. (1994). by David Goode. During the Rubella Syndrome epidemic of the 1960s, many children were born deaf, blind, and mentally disabled. David Goode has devoted his life and career to understanding such people's world, a world without words, but not, the author confirms, one without communication. This book is the result of his studies of two children with congenital deaf-blindness and mental retardation. Goode spent countless hours observing, teaching, and playing with Christina, who had been institutionalized since age six, and Bianca, who remained in the care of her parents. A World Without Words presents moving and convincing evidence that human beings both with and without formal language can understand and communicate with each other in many ways.

Why I Burned My Book and Other Essays on Disability (2003). by Paul K. Longmore. Understanding disability as a major variety of human experience, Longmore urges us to establish it as a category of social, political, and historical analysis in much the same way that race, gender, and class already have been. The essays here search for the often hidden pattern of systemic prejudice and probe into the institutionalized discrimination that affects the one in five Americans with disabilities. The title essay, which concludes the book, demonstrates the necessity of activism for any disabled person who wants access to the American dream. (Amazon)

Yes! She Knows She's There. Nicola Schaefer. Nicola Schaefer, a loving mother with the capacity to reflect and the ability to give meaning to experience, has written another chapter to bring us up to date about her daughter Catherine. While she's an extraordinary person, Nicola also reveals herself to be no different from any other mother: she worries she's unsure she has doubts; she makes mistakes. But she believes in life, in the potentialities of friendship, and in the gifts her daughter has to give. As is true about all great stories, this one touches your heart with its honesty and its everyday-ness. Nicola tells us about her struggles to support her family, about how she

gets tired, and about how she comes to realize that she needs time for herself. But it is delightful to learn how she takes care of it all without compromising her daughter's opportunities to take her own place in the world. Nancy Thaler.

Other Recommended Books (fiction and non-fiction, but not memoir-style)

Bus Girl: Poems, (1997) Gretchen Josephson. *Bus Girl* is a thought-provoking, often humorous collection of poems from a woman born with Down syndrome. With passages beginning from early adulthood, we read of Gretchen's development as she matures from parental dependence toward independence and adult relationships—including a romance and marriage. A self-taught poet, Gretchen's voice here is both direct and honest, and at times, cutting. Her experiences working in the Denver Dry Goods retail store as a bus-girl in the tea room form the core of this book: this is her sense of belonging and fitting into a world where she found purpose and success. When the store closes and Gretchen loses her job as bus girl it becomes immediately apparent how a sense of purpose and achievement is critical to us all. (Amazon).

Getting Life. (2002) Julie Shaw Cole. *Getting Life* gets into the mind of the primary character in a way that draws you into her world so completely you don't want to let her go. What makes this so interesting a task is that as the novel begins the protagonist, Emily, is a non-verbal, nursing home resident who has sat like a lump on a borrowed wheelchair for most of the past seventeen years. But Emily is not a lump; she is a thinking, feeling human being who has never had the opportunity to show her stuff. This is a triumphant story, but more importantly it's a fascinating one which takes us into the minds of several nursing home residents, touches on the lives of several staff members of an independent living center and includes an ADAPT-like group for emphasis. As I read, my only regret was that not every town has an independent living center like the one in the book - patient, knowledgeable, resourceful, and persistent. Advocado Press.

Honor Thy Son. (1994). Lou Shaw. Jack Ingraham deserts his family when his first child, J.J., is born with a disability. Years later J.J. is implicated in a murder, and Jack gets involved with his son for the first time. "As soon as I started reading, I could see J.J. in my mind. I love the suspense."-- Chris Burke, star of "Life Goes On."

In This Sign (1984). Joanne Greenberg. Joanne Greenberg has taken the world of the deaf and made it an extension of everyone's experience-and made it a metaphor for childish innocence, for grown-up alienation and loneliness . . . and for the inability of all of us to truly listen and speak. - *The New York Times*

The Memory Keeper's Daughter (2006). Kim Edwards. Fiction. The story is about a family in the 1960's who have twins & one of them has Down syndrome. The father a doctor asks his nurse to take the baby to an asylum but the nurse instead raises the child herself. The mother of the baby never is told. Their story is not just about Down syndrome but some really nice things are woven in the story about expecting your child w/a disability can learn, starting support groups, fighting w/schools for inclusion, the IDEA, etc. It also shows how a family is torn apart by an unknown secret.

More Than a Mom: Living a Full and Balanced Life When Your Child Has Special Needs. (2006). Amy Baskin & Heather Fawcett Explores how women can lead rich, fulfilling personal lives while parenting a child with special needs. The authors' skillful blend of research, personal

experiences, and survey feedback from over 500 mothers across North America results in a book that is jam-packed with practical strategies, advice, and reassurance for mothers trying to create more manageable and fulfilling lives.

The Power of the Powerless. Christopher de Vinck (be careful, there are other books out there with the same title). (non-fiction) Michael Lipsky's "Street-Level Bureaucracy," which revolves around the observation that in public services (and who knows where else?) "policy" is usually shaped--made, if you will--in the daily interactions of public service workers with members of the public.

Views from Our Shoes Growing Up with a Brother or Sister with Special Needs. (1997). Ed. Don Meyer/ Illustrated by Cary Pillo. Although the number of books about disabled children has grown steadily, not many nonfiction books explore the feelings of a disabled child's brother or sister. These unpretentious, honest snippets, contributed by 45 children ranging in age from 4 ("My Mommy and Daddy told me that Nicole was born very early and her brain got hurt") to 18, seek to fill that gap. In talking about their sibs and their feelings, the writers admit to embarrassment ("I'm sure glad he doesn't go to my school . . . if they find out that he's my brother, they'd laugh"), anger, and jealousy. But at the same time, they show how protective and loving and surprisingly wise they are when it comes to getting along in a family that is different. Stephanie Zvirin

We Are All Welcome Here. (2006). Elizabeth Berg (Fiction). Fourteen years ago, pregnant Paige Dunn was felled by a severe case of polio; she delivered her baby from an iron lung. Left alone after her husband abandoned and divorced her, she raised her daughter, Diana, alone. Diana, now 13, has taken over the night shift of her mother's round-the-clock nursing care. Out of this virtually shut-in situation, Elizabeth Berg has knitted a tight fiction about domestic strife and loyalty; racism; and the long aftermath of disease. Barnes & Noble.

We Dance Together, A Painted Essay about my Education with Katie. (2005). Candee Basford. a picture book that communicates the story of the author's education with her daughter Katie. The journey begins when the author learns of her daughter's disability and continues for the next twenty-six years weaving lessons of love, relationships, ambiguity and more. Painted and narrated by the author, *We Dance Together* features ten richly, evocative images, each revealing a lesson about self and society. The images depict her personal, often joyful revelations that lie in stark contrast to our society's history of negative attitudes and actions toward people with disabilities.

What About Me?: Growing Up with a Developmentally Disabled Sibling. A wonderful resource and one that families with disabled children have needed for a long time. Edward Ziegler, Ph.D., Yale University

For Children

The Best Worst Brother, (2005). Stephanie Stuve-Bodeen/illustrated by Charlotte Fremaux. This sequel to *We'll Paint the Octopus Red* (Woodbine, 1998) follows the relationship between three-year-old Isaac, who has Down's syndrome, and his older sister, Emma, who is frustrated by his slow language and motor development. Because he does not yet have the skills required for speech, the family attempts to teach him sign language. Emma works hard to make her brother understand, but he doesn't seem to make much progress. However, by the end of the book, he demonstrates that he is capable of learning, albeit at a slower pace than she expects. Emma, in

turn, shows more understanding of his developmental disability and takes great pleasure in his successes. Amazon.

Petey. (2000). Ben Mikaelson. A novel about the relationship between a teenager and a man mistakenly institutionalized for much of his life. Part one of the novel relates Petey's "backstory": in 1922, at the age of two, his distraught parents commit him to the state's insane asylum, unaware that their has severe cerebral palsy. Petey avoids withdrawal and depression despite the horrific conditions in his new "home" and, over the course of 60 years, caretakers befriend but then leave him. The point of view in part two shifts from Petey to Trevor, an eighth-grader suffering from both lack of friends and lack of parental attention after a series of moves. Trevor finds the answer to his needs in an unlikely friendship with the 70-year-old Petey, who has moved to a nursing home. Ages 10-up. Copyright 1998 Reed Business Information, Inc.

Stuck in Neutral. (2001). Terry Trueman . A truly unique journey into the mind of a truly unique character. Shawn McDaniel, who is literally trapped in his own body, will serve as a powerful metaphor for teens who feel cornered by circumstances or their own physical shortcomings. Terry Trueman's first-person portrayal of Shawn is made all the more poignant by the fact that Trueman's own son, Henry, also has cerebral palsy. This is an original and moving debut. (Ages 11 to 15) -- Jennifer Hubert

We'll Paint the Octopus Red. (1998). Stephanie Stuve-Bodeen/ Illustrated by Pam DeVito. Emma isn't happy to learn that she will soon be a big sister. After talking with her father, however, she thinks of "at least a million things my new brother or sister could do with me," and she eagerly awaits her sibling's arrival. When Isaac is born, the family is confronted with the fact that he has Down Syndrome. Emma's father explains that Isaac will still be able to do all of the things that Emma has thought of; he will just do them at a slower pace. The story ends on a high note with an excited Emma and her father visiting Isaac and her mother in the hospital. (K-3). School Library Journal.