

Recommended Books About the Disability Experience

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The original intention of the following list of recommended books was to provide students in a disability studies class with a list of resources that could give an “insider’s view” of a disability experience from various approaches, perspectives, and types of disability. Many people graciously contributed books that have illuminated the disability experience for them, books that have informed them of the injustices that have occurred – and continue to occur – toward people with disabilities, or books that have reflected their own experiences. This list, however, is not – and may never be – fully complete. If you have favorite memoir-style books that you think should be included, please forward us information about the book. This list includes months of good reads...we hope you will enjoy exploring these books and getting a more personal understandings of people's many different disability experiences.

These books are divided into the following sections: The first section presents books written by people with disabilities or by family members. Most are memoir-style accounts. They convey the experience of disability through first person accounts. Some are collections of essays and other writings by people with disabilities. Following this list are some additional recommendations which include fiction, non-fiction, books for children, and films. Several of the following suggested books are from the Disability Studies: Information and Resources List edited and compiled by Taylor, Shoultz, and Walker (2003), with contributions from Jagdish Chander, Beth Ferri, Perri Harris, Lori Lewin, Michael Schwartz, Zach Rosetti, Julia White, and Rachael Zubal-Ruggieri, for the National Resource Center on Supported Living and Choice, Center on Human Policy, School of Education, Syracuse University. Unless otherwise noted, the list of films and their synopses are from the Disabilities Studies list (Taylor, Shoultz, and Walker, 2003), as well. For more information on the Syracuse University Disability Studies list, please

visit: http://thechp.syr.edu/Disability_Studies_2003_current.doc. For larger lists of documentaries, including major motion pictures, two sources are the UC Berkeley Media Resources Center lists about the disability experience (<http://www.lib.berkeley.edu/MRC/disability.html>) or Films Involving Disabilities (<http://www.caravan.demon.co.uk>).

Recommended Books about the Disability Experience

Barron, J., & Barron, S. (1992). *There's a boy in here*. New York: Simon & Schuster.

There's A Boy In Here tells two stories: that of the mother of a child with autism, and that of the child. Barron describes in great detail her son Sean's difficult behaviors, his tantrums, his compulsions and fixations, his seeming indifference to his family, and her own tumultuous efforts to simultaneously understand his behaviors and help him diminish them. Sean then retells some of these accounts with his own memories of these events; in particular, he emphasizes how these behaviors were not only pleasurable for him, but were an attempt to control his environment and lessen the possibilities of failure. Except for nine months he spent in a residential school, Sean was fully included in general education throughout his schooling and Sean provides a detailed perspective of his classroom experiences. While the account provides the perspectives of both the parent and the person with autism, unfortunately, the narrative ultimately reinforces the idea that autism is something to be cured or overcome (Source: Center on Human Policy, Syracuse University).

Bauby, J. (1997). *The diving bell and the butterfly*. New York: Alfred A. Knopf.

On December 8 1995, *Elle* magazine editor-in-chief Bauby suffered a stroke and lapsed into a coma. He awoke 20 days later, mentally aware of his surroundings but physically paralyzed with the exception of some movement in his head and left eye. Bauby had Locked-in-Syndrome, a rare condition caused by stroke damage to the brain stem. Eye movements and blinking a code representing letters of the alphabet became his sole means of communication. It is also how he dictated this warm, sad, and extraordinary memoir. Bauby's thoughts on the illness, the hospital, family, friends, career, and life before and after the stroke appear with considerable humor and humanity. Actor Rene Auberjonois's narration adds to the poignancy of the story. Sadly, Bauby died of his condition in 1997 (Source: Stephen L. Hupp, Univ. of Pittsburgh at Johnstown Lib., Library Journal, Amazon.com).

Beck, M. (2000). *Expecting Adam: A true story of birth, rebirth, and everyday magic* (Reissue ed.). New York: Berkley.

Expecting Adam is 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 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 (Source: Excerpted from Ericka Lutz, Amazon.com). Recommended by Donna Martinez, Co-Vice President, National Coalition on Self Determination; and Sue Swenson, Executive Director, The Arc of the United States.

Bérubé, M. (1996). *Life as we know it: A father, family, and an exceptional child.* New York: Vintage Books.

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, what kind of society is valued, and by what means we determine this value (Source: Center on Human Policy, Syracuse University).

Blackman, L. (1999). *Lucy's story: Autism and other adventures.* Mt. Ommaney, Australia: Book in Hand.

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. (Source: Center on Human Policy, Syracuse University).

Bogdan, R., & Taylor, S. J. (1994). *The social meaning of mental retardation: Two life stories.* New York: Teachers College Press.

The concept of mental retardation is challenged through life histories based on in-depth interviews with former residents of institutions for people labeled mentally retarded. The authors argue that mental retardation is not a real entity, but rather a social construction (Source: Center on Human Policy, Syracuse University). Recommended by Phil Smith, Assistant Professor, Special Education, Eastern Michigan University.

Brown, C. (1998). *My left foot.* London: Vintage. (Original work published 1954).

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 (Source: BookRags.com).

Brown, S.E. (2003). *Movie stars and sensuous scars, essays on the journey from disability shame to disability pride*. Lincoln, NE: iUniverse.

Movie Stars and Sensuous Scars: Essays on the Journey from Disability Shame to Disability Pride is a combination of autobiographical stories about living with a disability, scholarly essays about disability rights and disability culture, and profiles of disability rights leaders, in the context of a world-wide disability rights movement by Steven E. Brown, Ph.D., Co-Founder, Institute on Disability Culture, and Resident Scholar, Center on Disability Studies at the University of Hawai'i, who is an internationally-renowned disability rights activist. Brown is a historian and award-winning poet, Brown's written five books about disability rights and culture and six books of poetry (Source: DisabilitiesBooks.com). Recommended by Mary Cerreto, Associate Professor of Family Medicine, Boston University.

Buck, P.S. (1992). *The child who never grew*. Bethesda, MD: Woodbine House. (Original work published 1950).

This edition brings back into print a classic in disability literature. Written by a Nobel and Pulitzer prize-winning author, this personal account broke a national taboo when it was originally published in 1950. Buck's inspiring account of her struggle to help and understand her daughter with mental retardation was perhaps the first disclosure of its kind by a public figure. Today, much of the emotional experience Buck so eloquently describes still rings true. New material written especially for this edition amplifies her story and gives the book an important historical perspective (Source: WoodbineHouse.com). Recommended by Diana Lawrence-Brown, Chair, Inclusive Graduate Programs, St. Bonaventure University; Deborah Safarik; and Sue Swenson, Executive Director, The Arc of the United States.

Brantlinger, E., Klein, S., & Guskin, S. (1994). *Fighting for Darla: Challenges for family care and professional responsibility: The case study of a pregnant adolescent with autism*. New York: Teachers College Press.

From the authors' Foreword: "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...." (Source: Excerpted from Ontario Adult Autism Research

and Support Network Book Review, www.ont-autism.uoguelph.ca/). Recommended by Phil Smith, Assistant Professor, Special Education, Eastern Michigan University.

Callahan, J. (1989). Don't worry, he won't get far on foot. New York: Vintage Books.

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 his experiences and lessons learned in a straightforward way that does not allow pity or ego to enter the picture (Source: Center on Human Policy, Syracuse University).

Clare, E. (1999). Exile & pride: Disability, queerness, and liberation. Cambridge, MA: South End Press.

Eli Clare investigates disability, class, queerness, child sexual abuse, and conflicting political and environmental awarenesses, using the metaphors of landscape and her own experience. She recalls and brings to life images of the mountains and forests, rivers and oceans of her childhood in rural Oregon, her body, and her many homes, in these musings on home, exile, politics and experience (Source: Center on Human Policy, Syracuse University).

Crane, G.T. (2004). Aidan's way: The story of a boy's life and a father's journey. Naperville, IL: Sourcebooks.

Sam Crane was unprepared to be the father of Aidan, a boy who would never walk, talk or see. Aidan's Way is an endlessly inspiring account of parental love and devotion, of the lessons of ancient eastern philosophy and of what it means, ultimately, to be human (Source: SpecialNeeds.com). Recommended by Susan Marks, Associate Professor, Northern Arizona University.

Crimmins, C. (1991). Where is the mango princess? New York: Knopf.

Although it was frightening when Crimmins's husband, Alan, an attorney, suffered a traumatic brain injury 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 (Source: Excerpted from Kim Witherspoon, Publisher's Weekly, Amazon.com).

De Vinck, C. (1988). The Power of the powerless. New York: Doubleday.

De Vinck writes about his brother Oliver, who lives a life of profound disability, and shows how much Oliver means to him and to all he comes in contact with. Oliver "lay in the same bed for 33 years, unable to see, walk, communicate or feed himself." The book jacket says the book "is a doorway into the deep lessons of life, love, and faith Christopher de Vinck learned from his brother Oliver. It poignantly affirms the immeasurable worth of every person." The book has introductory and closing remarks by Henri Nouwen, Sargent Shriver and Fred (Mr.) Rogers. Recommendation and review by David Coulter, M.D., Department of Neurology, Children's Hospital, Boston, Massachusetts.

Dorris, M. (1989). *The broken cord*. New York: Harper Perennial.

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 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. The volume includes a short account of his own life by the 20-year-old Adam, and a foreword by Dorris's wife, the writer Louise Erdrich. *The Broken Cord* won a National Book Critics Circle Award in 1989 (Source: Amazon.com).

Dubus, A. (1998). *Meditations from a movable chair: Essays*. New York: Vintage.

His second essay collection, *Meditations from a Movable Chair*, is about the people who have meant the most to him. The book conjures a cloud of witnesses--Dubus's father, his sister, Norman Mailer, Liv Ullmann, a gay military officer--so vividly that their gifts to Dubus become gifts to the reader, as well. Many of these people helped Dubus understand the holiness, even sacramentality, of everyday life, which he describes in explicitly Catholic terms. *Meditations from a Movable Chair* is a rare and wonderful thing--a book written out of love, whose richness of heart is expressed by an exacting and challenging mind (Source: Michael Joseph Gross, Amazon.com).

Fadiman, A. (1997). *The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures*. New York: Farrar, Straus & Giroux.

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 (Source: Center for Disabilities Studies, University of Delaware).

Featherstone, H. (1981). *A difference in the family* (2nd ed.). New York: Basic Books.

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 (Source: Publisher book description, Amazon.com). Recommended by Jamie Ruppman, Associate Director, The Advocacy Institute; Sue Swenson, Executive Director; The Arc of the United States; and Lynne Tamor, Parent and Advocacy Coordinator, Association for Children's Mental Health.

Fries, K. (1997). *Body, remember*. 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 (Source: Center on Human Policy, Syracuse University).

Fries, K. (Ed.). (1997). *Staring back: The disability experience from the inside out*. New York: Plume.

This book explores the experience of disability through writings by contributors who have disabilities. The collection includes nonfiction, poetry, fiction, and drama by such authors as Nancy Mairs, John Hockenberry, Anne Finger, Adrienne Rich, Mark O'Brien, and Marilyn Hacker. Each chapter explores disability not as something that limits one's life, but as an experience all its own. Fries considers the theme of this edited book as one of human connection, "connection with the past, connection with one another, connection with our bodies, connection with ourselves." (Source: Center on Human Policy, Syracuse University).

Galli, R. (2000). *Rescuing Jeffrey*, Chapel Hill: Algonquin Books.

In one terrible instant, on July 4, 1998, the lives of the Galli family changed forever. Their 17-year-old son dove into a pool and broke his neck when his head hit the bottom. So begins the account of the next 10 days in Jeffrey's life as told by his father. When the Gallis were informed that their son's fracture had resulted in quadriplegia, their world crumbled. As doctors, specialists, social workers, and clergy tried to explain the future that Jeffrey was facing, his parents started to consider another possibility. Perhaps life under those conditions was not the best choice for their son-maybe the best option for Jeffrey was death. This is an honest and heartrending account of a family facing a dire reality (Source: Excerpted from Carol DeAngelo, Kings Park Library, Burke, VA, School Library Journal).

Gill, B. (1997). *Changed by a child*. New York: Doubleday.

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. (Source: RandomHouse.com). Recommended by Sue Swenson, Executive Director, The Arc of the United States; and Susan Yuan, Associate Director, Center on Disability and Community Inclusion, University of Vermont.

Gottlieb, D. (2006). *Letters to Sam: A grandfather's lessons on love, loss, and the gifts of life*. New York: Sterling Publishing Co., Inc.

In the tradition of such bestsellers as *Tuesdays with Morrie*, this is a powerful collection of love letters from a quadriplegic grandfather to his autistic grandson. Written by award-winning radio host and psychologist Daniel Gottlieb, it is sure to touch readers deeply. (Source: SpecialNeeds.com).

Grandin, T. (1995). *Thinking in pictures: And other reports from my life*. New York: Bantam.

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 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 (Source: Center on Human Policy, Syracuse University). Recommended by Mary Cerreto, Associate Professor of Family Medicine, Boston University.

Grandin, T., & Scariano, Margaret M. (1986). *Emergence: Labeled autistic*. Novato, CA: Arena Press.

Temple Grandin's groundbreaking book chronicles the remarkable and inspiring true story of how she overcame autism-with a new introduction. Temple 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, autistic 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 (Source: Book Description, Amazon.com). Recommended by Deb Einhorn, Director, Family Matters, Family Support Program, Parent Training and Information Center and ARC Community Support System.

Grealy, L. (1994). *Autobiography of a face*. New York: HarperCollins.

The narrative's starting point of view is that of Grealy as a child, from her early diagnosis of cancer at age nine, replete with the singular distinction of being sick 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 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 (Source: Center on Human Policy, Syracuse University).

Greenfeld, J. (1989). A child called Noah. (Reissue ed.). New York: Pocket Books.

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. No matter what the label - autistic or severely retarded - Noah was a child who would grow old but would never grow up, and for whom no cure is available. 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. A Child Called Noah is an honest, harrowing, and profoundly human story (Source: Wyoming Parent Information Center, <http://www.wpic.org/>).

Hale, M.J.G., & Hale, Jr., C.M. (1999). I had no means to shout. Bloomington, IN: 1st Books.

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" (Source: Center on Human Policy, Syracuse University). Recommended by Cornelia Moisuk, Parent.

Hall, M.L. (1998). Dazed and fatigued in the toxic 21st century (1998). Los Angeles: Consafos.

In his senior year at UC Berkeley, author Mark Llewellyn Hall comes down with a mysterious illness. His quest for a cure forces him to completely transform his life, which ultimately becomes the key to his miraculous recovery. Written in a young, alternative voice that weaves powerful prose with original poetry, "Dazed and Fatigued in the Toxic 21st Century" reveals a remarkable story of determination and personal insight, that sheds new light on what it means to grow up and live in today's toxic age. (Source: Book Description, Amazon.com).

Harland, K. (2002). A will of his own: Reflections on parenting a child with autism. Bethesda, MD: Woodbine House.

Reflecting on her life before and after motherhood, Harland finds that despite the pain and chaos of Will's autism, her life's horizon has stretched and grown. Her son's disorder has pulled her in directions she never meant to go, but wouldn't reverse for anything. *A Will Of His Own* should be enjoyed by other parents whose child has taken them into uncharted territory, as well as by readers who want to imagine what that journey entails. (Source: Excerpted from publisher book description, WoodbineHouse.com). Recommended by Deanna Pedicone, Project Coordinator, Center for Disabilities Studies, University of Delaware.

Hockenberry, J. (1995). Moving violations: War zones, wheelchairs, and declarations of independence. New York: Hyperion.

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 renowned 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 (Source: Center on Human Policy, Syracuse University). Recommended by Maureen Keyes, Associate Professor, University of Wisconsin – Milwaukee.

Jacobs, M.B. (2006). Secret girl. New York: St. Martin's Press.

Secret Girl is a memoir about a well-to-do Baltimore family that for decades guarded a secret they felt too ashamed to reveal, much less discuss among themselves. When Brucie Jacobs, the family's eldest daughter, finds herself newly sober at the age of 38, she finally seeks out and comes face-to-face with this secret—a younger sister Anne who was diagnosed at birth with hydrocephalus and mental retardation, then institutionalized. Anne has never been home to visit, and Jacobs has never seen her. This memoir goes beyond the story of simply one family; it sheds light upon the struggle for human connection that we all share, and upon the need to accept one's limitations, as well as to learn forgiveness (Source: MollyBruceJacobs.com). Recommended by Steve Eidelman, Robert Edelson Professor, Department of Individual and Family Studies, University of Delaware; and Liz Weintraub, Quality Enhancement Specialist, Council on Quality in Leadership.

Jezer, M. (1997). Stuttering: A life bound up in words. New York: Basic Books.

Despite his participation in several forms of treatment, Jezer did not achieve fluency. His memoir tells of his experiences with dysfluency but also of his successes and

satisfactions in professional and personal life (Source: Ray D. Kent, <http://www.mnsu.edu/comdis/kuster2/therapy/firstperson/consumerbooks.html>).

Johnson, H.M. (2006). *Too late to die young: Nearly true tales from a life*. New York: Picador.

With a voice as disarmingly bold, funny, and unsentimental as its author, a thoroughly unconventional memoir that shatters the myth of the tragic disabled life. Harriet McBryde Johnson isn't sure, but she thinks one of her earliest memories was learning that she will die. The message came from a maudlin TV commercial for the Muscular Dystrophy Association that featured a boy who looked a lot like her. Then as now, Johnson tended to draw her own conclusions. In secret, she carried the knowledge of her mortality with her and tried to sort out what it meant. By the time she realized she wasn't a dying child, she was living a grown-up life, intensely engaged with people, politics, work, struggle, and community. Due to a congenital neuromuscular disease, Johnson has never been able to walk, dress, or bathe without assistance. With help, however, she manages to take on the world. From the streets of Havana, where she covers an international disability rights conference, to the floor of the Democratic National Convention in Chicago, to an auditorium at Princeton, where she defends her right to live against philosopher Peter Singer, she lives a life on her own terms. And along the way, she defies and debunks every popular assumption about disability (Source: Excerpted from Book Description, Amazon.com). Recommended by Fredda Brown, Professor, Special Education, Department of Educational and Community Programs, CUNY/Queens College, Division of Education.

Johnson, R., & Williams, K. (1999). *Lost in a desert world: The autobiography of Roland Johnson*. Wallace, CA: Massey-Reyner.

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 (Source: Excerpted from Book Description, Amazon.com). Recommended by Ruthie Marie Beckwith, Director, Tennessee Microboards Association; Donna Martinez, Co-Vice President, National Coalition on Self Determination; Phil Smith, Assistant Professor, Special Education, Eastern Michigan University; and Liz Weintraub, Quality Enhancement Specialist, Council on Quality in Leadership.

Karasik, P., and Karasik, J. (2003). *The ride together: A brother and sister's memoir of Autism in the family*. New York: Washington Square.

In this remarkable book, the Karasiks present a sibling's viewpoint of growing up with autism. Alternating between Judy's memoir and Paul's comics, they chronicle the life of their brother, David, from the 1950s to today. The authors recount the heartbreaks and joys of growing up with an autistic sibling and offer insights into the treatment of the condition at a time, when the medical and educational professions knew little about it and blamed parents (namely, "refrigerator moms"). Events such as David's recitations of whole TV shows and his slapping his head as a response to uncomfortable situations take on new meaning through the unique format. Judy formerly worked as a book editor, and Paul is a professional cartoonist. Their book fills an important gap in the literature, complementing the parental view found in most autism narratives. This work is strongly recommended for all public libraries and academic libraries with collections on autism and disability studies, as well as for book groups that wish to include a graphic novel. Given the focus on children with special needs, secondary school libraries should also consider it (Source: Corey Seeman, Univ. of Toledo Libs., OH, School Library Journal, Amazon.com). Recommended by Karen Lee, Executive Director, SEEC.

Kaufman, B., & Kaufman, R. (1994). *Son-rise: the miracle continues (Reprint ed.)*. Tiburon, CA: H.J. Kramer.

The original *Son-Rise* (1976) described the family trauma of the author, his wife Samahria and their son Raun, who had been diagnosed as autistic, mentally retarded and untreatable. Rather than relegating Raun to permanent institutionalization, the Kaufmans designed a program of their own, which provided intensive therapy on a rigorous schedule that changed all of their lives. Did Raun continue to progress? In this book, that question is answered not only by the parents and extended family but also by Raun himself, now a college student and a participant in the family's educational foundation, The Option Institute and Fellowship, based in Sheffield, Mass. Testimonials from similarly afflicted families who practice the Kaufmans' techniques for treating the communications disorders of so-called "unreachable" children round out a heartwarming, inspiring chronicle that should offer hope to many (Source: Publishers Weekly, Amazon.com). Recommended by Ron Taylor, Independent Filmmaker.

Kaufman, S. (1999). *Retarded isn't stupid, mom! (Rev. ed.)*. Baltimore: Paul H. Brookes.

Nicole is 2 years old, and her family, after months of worrying, has just learned she has mental retardation. In a fast-paced, engaging story, mother Sandra Kaufman frankly reveals the feelings of denial, guilt, frustration, and eventual acceptance that result in a determination to help her child live an independent life. This edition, revised on the 10th anniversary of the book's original publication, adds a "progress report" that updates readers on Nicole's adult years and reflects on the revolutionary changes in society's attitudes toward people with disabilities since Nicole's birth. *Retarded Isn't Stupid, Mom!* remains a celebration of all that a child can grow to be (Source: BrookesPublishing.com).

Recommended by Cynthia Levine, Shrieber Clinical Services Corporation (who remembered this book being recommended by Rosemary Dybwad).

Keith, L. (Ed.). (1994). *Mustn't grumble: Writings by disabled women*. London: The Women's Press.

This book presents writings by other women who have a range of physical disabilities. The short stories and poems included in this book range in topic from issues of accessibility to abuse to equality. Disability is framed by these narratives as a social, cultural, and political issue, not only as a personal one. This is an excellent account of disability issues from a woman's perspective. It is powerful, moving, and educating for all readers (Source: Center on Human Policy, Syracuse University).

Keith, L. (Ed.) (1996). "What happened to you?": Writing by disabled women. New York: The New Press.

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 (Source: Barbara M. Bibel, Oakland P.L., Cal., Library Journal, Amazon.com).

Kingsley, J, and Levitz, M. (1994). *Count us in: Growing up with Down syndrome*. San Diego: Harvest Books.

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 (Source: Denise Perry Donavin, Booklist, Amazon.com). Recommended by Diana Lawrence-Brown, Chair, Inclusive Graduate Programs, St. Bonaventure University; Deborah Safarik, Phil Smith, Assistant Professor, Special Education, Eastern Michigan University; and Liz Weintraub, Quality Enhancement Specialist, Council on Quality in Leadership.

Kisor, H. (1990). *What's that pig outdoors?: A memoir of deafness*. New York: Penguin Books.

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. With unflinching candor and telling details, Kisor cites the ways in which being deaf among

the hearing shaped his personal and professional experiences (Source: Publisher's Weekly, Amazon.com). Recommended by Maureen Keyes, Associate Professor, University of Wisconsin – Milwaukee.

Klein, S.D., & Kemp, J.D. (Eds.). (2005). Reflections from a different journey: What adults with disabilities want all parents to know. New York: McGraw-Hill.

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 (Source: DisabilitiesBooks.com). Recommended by Mary Cerreto, Associate Professor of Family Medicine, Boston University.

Kupfer, F. (1998). Before and after Zachariah: A family story about a different kind of courage. Chicago: Academy Chicago.

An intimate chronicle of one family's life with a young, severely neurologically disabled child. The author describes and defends the decision to place Zachariah in an institution. A teacher of writing, Ms. Kupfer has publicly and bitterly criticized families who decide to keep their children with disabilities at home. Even those who condemn this attitude, as we do, will nevertheless find this important reading (Source: SpecialNeeds.com). Recommended by Lynne Tamor, Parent and Advocacy Coordinator, Association for Children's Mental Health.

Kuusisto, S. (1998). Planet of the blind: A memoir. New York: Delta.

"A beautifully written account that graces the reader with painful insight and self-revelation" (Jo Holzer, CDR Executive Director). Kuusisto is a poet, a graduate of the Iowa Writer's Workshop, and a Fulbright scholar. He is currently director of student services at Guiding Eyes for the Blind, a nationally renowned guide dog school in Yorktown Heights, New York. Kuusisto has been legally blind since birth owing to a condition known as retinopathy of prematurity. In his memoir, he writes about his parents' denial of his blindness and his struggles to read and learn in a public school. The author describes his long-standing reluctance to accept his disability because he did not want to feel dependent, recounting his attempts to "pass" as sighted throughout childhood and into adulthood. The most hopeful passages of this compelling story occur near the end, when Kuusisto trains at Guiding Eyes for the Blind and receives his guide dog, Corky. Kuusisto's poetic prose is filled with perceptive reflections on the tribulations of blindness and common misconceptions about the blind (Source: Ximena Chrisagis, Fordham Health Sciences Lib., Wright State Univ., Dayton, Ohio, Library Journal, Amazon.com)

Lee, C., & Jackson, R. (1992). Faking it: A look into the mind of a creative learner. Portsmouth, NH: Heinemann.

Faking It is Chris Lee's story of almost two decades of academic frustration, matched by remarkable persistence, resilience, and ingenuity. It is a moving account of how people with his problems can be helped to overcome them. The story Chris tells of what happened to him when he wound up in the University of Georgia Learning Disabilities Adult Clinic, where he met Rosemary Jackson, is both a moving account of how people with his problems can be helped to overcome them and, at the same time, a powerful indictment of the system--and it is nationwide--that leaves people like Chris feeling incompetent and stupid (Source: SpecialNeeds.com). Recommended by Maureen Keyes, Associate Professor, University of Wisconsin – Milwaukee.

Linton, S. (2005) My body politic. Ann Arbor, MI: University of Michigan.

While hitchhiking from Boston to Washington, D.C., in 1971 to protest the war in Vietnam, Simi Linton was involved in a car accident that paralyzed her legs and took the lives of her young husband and her best friend. Her memoir begins with her struggle to regain physical and emotional strength and to resume her life in the world. Then Linton takes us on the road she traveled (with stops in Berkeley, Paris, Havana) and back to her home in Manhattan, as she learns what it means to be a disabled person in America (Source: Excerpted from University of Michigan Press description, <http://www.press.umich.edu/>).

Long, M.S. (1999). If your dreams are big enough, the facts don't count. Wallace, CA: Massey-Reyner.

Long's story is deceptively candid and truly intriguing. Clinically, Long has mild cerebral palsy and mental retardation arising from difficulties during his birth. Reading his life story in his words--getting inside his head in a sense--is an eye-opening experience. His story is not terrifically unique or absurd, which is part of the book's charm: the "fact" of his disability did not stand in the way of his dreams, nor should the reader's "disabilities," whether physical, mental or emotional, prevent them from fulfilling their own dreams. The book is honest and forthright. Long's goal with the book is to pass along his sense of confidence and fortitude, and remind readers that no matter how insurmountable their problems may seem, nothing is impossible. Long eventually became the first person with a developmental disability to be appointed to a government office by a state governor. (Source: Excerpted from Today's Librarian, September 2000, Virgo Publishing, Inc., http://www.karlwilliams.com/if_your_dreams.htm).

Lubchenco, L. O., & Crocker, A. C. (1997). Bus girl: Poems by Gretchen Josephson. Cambridge, MA: Brookline Books.

This book consists of 25 poems written by Gretchen Josephson, a woman with Down syndrome. She started writing poetry while still in her teens, when she began a job as a bus girl at a restaurant. Her poetry chronicles her life experiences with family, friends, love, and other areas of life. Josephson does not write about disability. Instead, she simply creates poetry about her life (Source: Center on Human Policy, Syracuse

University). Recommended by Phil Smith, Assistant Professor, Special Education, Eastern Michigan University.

Mairs, N. (1997). *Waist-high in the world: A life among the disabled*. Boston: Beacon Press.

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 (Source: Center on Human Policy, Syracuse University).

Marsh, J. (1995). *From the heart: On being the mother of a child with special needs*. Bethesda, MD: Woodbine House.

In *From the Heart: On Being the Mother of a Child with a Disability*, 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. *From the Heart* is organized around several themes: relationships with professionals; family life and school issues; and issues about the "self" and closest friends and family. Their experiences resonate with the common struggles of healing; being heard and understood; coping with life; and dealing with greater emotional intensity than most parents do. 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 (Source: Excerpted from Midwest Book Review, Amazon.com). Recommended by Lynne Tamor, Parent and Advocacy Coordinator, Association for Children's Mental Health.

Martin, R. (1994). *Out of silence*. New York: Henry Holt & Co.

The author's nephew Ian became autistic after his brain was damaged by a reaction to a routine vaccination for diphtheria, pertussis, and tetanus. The book is a graphic and scholarly account of autism but it also explores the essence of language learning, the child's attempt to cope with the objective world (Source: Ray D. Kent, <http://www.mnsu.edu/comdis/kuster2/therapy/firstperson/consumerbooks.html>).

Mason, M. (2000). *Incurably human*. London: Working Press.

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 (Source: Center on Human Policy, Syracuse University).

Matola, T., & Johnson, R. (2002). Don't pull the plug: A lesson in life. Los Gatos, CA: Intrepid.

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 (Source: DisabilitiesBooks.com). Recommended by Mary Cerreto, Associate Professor of Family Medicine, Boston University.

Meyer, D. (1995). Uncommon fathers: Reflections on raising a child with a disability. Bethesda, MD: Woodbine House.

Nineteen fathers of children with disabilities write about the loss they felt when their child was born and regaining the pride in their children. They talk about their own self-awareness as well as how other men and members of the community response to their children (Source: Center for Disabilities Studies, University of Delaware).

Miller, N. (1994). Nobody's perfect: Living & growing with children who have special needs. Baltimore, MD: Paul H. Brookes.

Four “moms” who have had a child with a disability talk about the feelings of loss, acceptance, support, set-backs, and rewards related to their children with special needs. Written in both first person accounts and from professional perspectives, this book examines the emotional, social, and functional impact of having a child with special needs (Source: Center for Disabilities Studies, University of Delaware).

Moise, L. (1980). As we grew up with Barbara. Fort Bragg, CA: Cypress House.

Shares the story of Barbara Moise, born with developmental special needs, and the trials that led to Barbara's growing independence. Includes overview of the resources available for persons with developmental disabilities and recommendations on important aspects of programs and services (Source: EdGateway.net). Recommended by Ronnie Cohn, Independent Evaluator; and Patty McGill Smith, Parent, Grandmother, Advocate, President, The Arc of Nebraska.

Moise, L. (1998). Barbara and Fred, grownups now. Fort Bragg, CA: Cypress House.

This is a definitive book for parents and social workers in the field of developmental disabilities. This book explores the issues and achievements of a mature couple tracing their growth from birth through significant and intimate relationships. There is not a hint of sentimentality here, just common sense, a bit of humor, political and social awareness, and an unflinching look at the life and times of an American family. The author feels that "attitudes are the real disability" (Source: SpecialNeeds.com). Contains a good list of resources. Recommended by Patty McGill Smith, Parent, Grandmother, Advocate, President, The Arc of Nebraska.

Mont, D. (2001). A different kind of boy: A father's memoir about raising a gifted child with autism. London: Jessica Kingsley.

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 (Source: Adapted from Jessica Kingsley book description, jkp.com). Recommended by Sue Swenson, Executive Director, The Arc of the United States.

Mukhopadhyay, T. R. (2000). Beyond the silence: My life, the world and autism. 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 (Source: Center on Human Policy, Syracuse University).

Murphy, R. F. (1987). The body silent: An anthropologist embarks on the most challenging journey of his life: Into the world of the disabled. 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 (Source: Center on Human Policy, Syracuse University). Recommended by Phil Smith, Assistant Professor, Special Education, Eastern Michigan University.

Murray, J. B., & Murray, Emily. (1975). And say what he is: The life of a special child. Cambridge, MA: MIT.

The parents of a "special child" who has a severe developmental disability write of their experiences and their growing recognition of the boy's personality and meaning to their lives (Source: Ray D. Kent, <http://www.mnsu.edu/comdis/kuster2/therapy/firstperson/consumerbooks.html>). Recommended by Susan Yuan, Associate Director, Center on Disability and Community Inclusion, University of Vermont.

Nazeer, K. (2006). Send in the idiots. London: Bloomsbury.

Nazeer, a successful British government policy adviser, was diagnosed early on with autism; he now seeks out the fate of four autistic classmates at his former New York City school. He first encountered the "idiots" (as one of them called the group) more than 20 years ago, in an unnamed private school that has subsequently closed. In addition to interviewing the former pupils, all but one (who committed suicide) enjoying varying degrees of success in the greater world, Nazeer also visits the school's former director and special-needs teacher to learn how teaching autistic students has evolved. Considered a neurobiological disorder, autism largely confines a child to his or her own mental world. André, for example, living in Boston with his sister, became a competent computer researcher and manages to mediate the challenges of ordinary conversation through the use of a puppet. Randall, a courier in Chicago, demonstrates how early "parallel" play led to a satisfying love relationship (developing empathy is difficult for the autistic). Craig became an accomplished speechwriter until his awkward social skills derailed him, while Elizabeth immersed herself in playing the piano before withdrawing completely. Nazeer delicately interweaves his own story of being "cured" for an enlightening journey through the unreachable mind (Source: Publisher's Weekly, Amazon.com). Recommended by Steve Drake and Phil Ferguson, E. Desmond Lee Professor in Education of Children with Disabilities, University of Missouri – St. Louis.

Nolan, C. (1987). Under the eye of the clock. New York: Arcade.

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. 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 (Source: Center on Human Policy, Syracuse University). Recommended by Mary Cerreto, Associate Professor of Family Medicine, Boston University; and Theresa Reborn, Parent of two young adults with disabilities, Assistant Director of Publications, Academy for Educational Development, National Dissemination Center for Children with Disabilities (NICHCY).

Palmer, G. (2005). *Adventures in the mainstream: Coming of age with Down syndrome*. Bethesda: Woodbine House.

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 (Source: Excerpted from publisher book description, WoodbineHouse.com). Recommended by Deborah Safarik.

Panzarino, C. (1994). *The me in the mirror*. Seattle: Seal Press.

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 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 (Source: Center on Human Policy, Syracuse University).

Park, C.C. (1982). *The siege: The first eight years of an autistic child*. (Rev. ed). Boston: Little, Brown.

At age two, in 1960, Jessy Park was withdrawn, unable to walk or talk, yet oddly content within the invisible walls that surrounded her. The study of autism was still in its infancy. This powerfully moving book charts a surprising journey of discovery as it records the challenges and rewards of the first eight years of Jessy's life (Source: Book Description, Amazon.com). Phil Ferguson writes: "Park is an English professor and writes in a way that I found both honest and insightful." Recommended by Phil Ferguson, E. Desmond Lee Professor in Education of Children with Disabilities, University of Missouri – St. Louis.

Park, C.C. (2001). *Exiting Nirvana: A daughter's life with autism* (Reprint ed.). Back Bay Books.

Reprising her own now classic work *The Siege*, which covered the early years of her autistic daughters' life, Clara Claiborne Park gives us a moving, eloquent portrait of Jessy as an autistic adult still struggling with language, with hypersensitivities and obsessions, and with the social interactions that most of us take for granted, but at the same time achieving more than her parents could have ever hoped for, becoming an accomplished artist, and growing into an active member of her family and community (Source: Book Description, Amazon.com). Recommended by Phil Ferguson, E. Desmond Lee Professor in Education of Children with Disabilities, University of Missouri – St. Louis.

Pieper, E. (1976). *Sticks and stones*. Syracuse, NY: Human Policy Press.

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. Review and Recommendation by Jack Yates, Secretary-Treasurer, Ohio Safeguards.

Price, R. (2003). *A whole new life* (Reprint ed.). New York: Scribner.

Price is James B. Duke Professor of English at Duke University. He came to disability as a mature and successful man and writer. He describes the experience in a very moving way and in plain, beautiful English. He also manages to find joy and meaning in the whole experience. Review and Recommendation by Cornelia Moisuk, Parent.

Prince-Hughes, D. (2004). *Songs of the gorilla nation: My journey through autism*. New York: Harmony Books.

In this elegant and thought-provoking memoir, Dawn Prince-Hughes traces her personal growth from undiagnosed autism to the moment when, as a young woman, she entered the Seattle Zoo and immediately became fascinated with the gorillas. Having suffered from a lifelong inability to relate to people in a meaningful way, Dawn was surprised to find herself irresistibly drawn to these great primates. By observing them and, later, working with them, she was finally able to emerge from her solitude and connect to living beings in a way she had never previously experienced. *Songs of the Gorilla Nation* is more than a story of autism, it is a paean to all that is important in life. Dawn Prince-Hughes's evocative story will undoubtedly have a lasting impact, forcing us, like the author herself, to rediscover and assess our own understanding of human emotion (Source: Book Description, Amazon.com). Recommended by Deb Einhorn, Director, Family Matters, Family Support Program, Parent Training and Information Center and ARC Community Support System.

Rabin, R. (1985). *Six parts love: One family's battle with Lou Gehrig's disease*. New York: Scribner.

This biography of the author's father follows him and his family as they face the trials of amyotrophic lateral sclerosis, a degenerative neurological disease. He was diagnosed with

ALS in June of 1979 and died in October 1984, conforming to the usual prognosis of death following diagnosis within 3 to 5 years (Source: Ray D. Kent, <http://www.mnsu.edu/comdis/kuster2/therapy/firstperson/consumerbooks.html>).

Reston, J. (2006). *Fragile innocence: A father's memoir of his daughter's courageous journey*. New York: Harmony.

Reston writes about his third and youngest child, Hillary, who as a toddler was struck with an unknown medical condition that left her developmentally disabled and with a host of other medical problems. He makes it clear that the state of his daughter's health has severely impacted her family members' lives. He makes no bones about the demands her condition has placed on them, just as he shows how much she means to them and to the many other people in her life. The book takes a strong stand in favor of cutting-edge medical research and putting the needs of the disabled in the planning and service forefront of any national health-care plan. This work could have been a tale of suffering or of triumph over adversity as Hillary survived some close calls and continues to live a rich life, yet her father tells a much more nuanced and enjoyable story (Source: Ted Westervelt, Library of Congress, Washington, DC, School Library Journal, Amazon.com). Recommended by Karen Lee, Executive Director, SEEC.

Russell, M. (1998). *Beyond ramps: Disability at the end of the social contract: A warning from an uppity cripp*. Monroe, ME: Common Courage.

Marta Russell exposes the neoliberal drive to shrink social services with the Reinventing Government mantra. "We are dangerously close to a Jerry Lewis democracy where middlemen beggars and corporate CEOs getting huge paychecks may replace entitlements with charity," reveals Russell in her devastating analysis of the "reform" of the social safety net. (Source: Book Description, Amazon.com). Recommended by Maureen Keyes, Associate Professor, University of Wisconsin – Milwaukee.

Schaefer, N. (2000). *Does she know she's there?* (2nd ed.). Garden City, NY: Doubleday.

First published in 1978, *Does She Know She's There?* is the inspiring story of one family's determination to love, cherish, and keep their only daughter. From the moment the Schaefer's were told their first-born Catherine would never walk, or talk, or even feed herself, they swore that to institutionalize her would be their last resort. The keeping of that vow was far from the story of tears and despair that some would assume. "Cath" emerges as an engaging personality in her own right, as terribly challenged as she is. Now 37, Catherine Schaefer lives in her own home, with live-in support, plus friends-cum-tenants in the upstairs apartments. Still unable to move much, or to speak, Catherine's life has, nevertheless, been a rewarding success story. This book is its chronicle, illustrated with black and white photographs (Source: Book Description, Amazon.com). Recommended by Diana Lawrence-Brown, Chair, Inclusive Graduate Programs, St. Bonaventure University; and David Wetherow, CommunityWorks.

Schaefer, N. (1996). Yes! She knows she's there. Toronto, ON: Inclusion Press.

Nicola Schaefer has done it again! Her first book (a best seller) regaled us with the struggles of Catherine (her daughter) and Nicola enroute to making a life. Now, a decade after Catherine moved into her own home in Winnipeg, that story - told as only Nicola can. A 'must read' for every family even thinking about dealing with children approaching adulthood. A powerful vision of hope, laced with reality and a liberal dash of fun. (Source: Inclusion.com). Recommended by Diana Lawrence-Brown, Chair, Inclusive Graduate Programs, St. Bonaventure University; and David Wetherow, CommunityWorks.

Sellin, B. (1995). I don't want to be inside me anymore: Messages from an autistic mind (A. Bell, Trans.). New York: Basic Books.

Sellin is a 21-year-old autistic German who has written a slender volume of epigrammatic musings using the technique of facilitated communication, 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 (Source: Nina Wikstrom Aguilar, MLS, Melbourne, Fla., Library Journal, Amazon.com). Recommended by Phil Smith, Assistant Professor, Special Education, Eastern Michigan University.

Shaw, B. (Ed.). (1994). The ragged edge: The disability experience from the pages of the first fifteen years of the disability rag. Louisville, KY: Advocado.

"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." (Source: Nancy Mairs, author of Plaintext, Carnal Acts, Ordinary Time and Waist High In the World, AvacadoPress.org). Recommended by Mary Cerreto, Associate Professor of Family Medicine, Boston University.

Sienkiewicz-Mercer, R., & Kaplan, S. B. (1989). I raise my eyes to say yes. New York: Avon Books.

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 (Source: Center on Human Policy, Syracuse University). Recommended by Mary Cerreto, Associate Professor of Family Medicine, Boston University; Linda Lengyel, Assistant Professor, Duquesne University; Cynthia Levine, , Shrieber Clinical Services Corporation; Ruby Moore, friend of Ruth's for 28 years and Executive Director, Georgia Advocacy Office; Lori Noto, Professor, School of Education and Human Resources, University of Bridgeport; and David Wetherow, CommunityWorks.

Simon, R. (2003). *Riding the bus with my sister*. New York: Plume.

When the book opens, Beth is spending her days riding the buses in the city where she lives, creating powerful connections with the drivers and passengers. Rachel, a driven professor and writer, is struggling to come to terms with her own ambitions and loneliness — as well as her distant feelings toward her one-of-a-kind sister. One day, Beth invites Rachel to join her for a year on the buses. Rachel says yes, and so begins a journey that changes both sisters' lives. (Source: RachelSimon.com). Recommended by Diana Lawrence-Brown, Chair, Inclusive Graduate Programs, St. Bonaventure University.

Simons, R. (1987). *After the tears: Parents talk about raising a child with a disability*. San Diego: Harvest Books.

Preface states, "In parenting a child with a disability, you face a major choice. You can believe that your child's condition is a deathblow 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." Well-written book with sections on guilt and anger, adjustments, isolation, marital stress, relatives, siblings, other family needs, strangers, professionals, the school system, meeting one's own needs, chronic sorrow, communication, and personal growth. Highly recommended for both parents and professionals. (Source: The Arc Minnesota, <http://www.arcminnesota.com/res-parents.htm>).

Speciner, J., & Godwin, P. (2006). *Finally, dreams coming true*. Lulu.com: Author.

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 (Source: Lulu.com)

Taylor, R. (1991). *All by self: A fathers story about a differently-abled child*. Boulder, CO: Light on Books & Videotapes.

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. The first chapter is illustrated by Jay Jacoby, and the second chapter ("Bonsai: The Art of Swimming through Life's Challenges") is illustrated by Micah and his brother Jonah. Review and Recommendation by Ron Taylor, Independent Filmmaker [for copies, contact author at lightoncom@aol.com].

Thompson, K., & Andrezjewski, J. (1989). *Why can't Sharon Kowalski come home?* Denver, CO: Spinsters Ink.

This book by Karen Thompson, a woman whose lover Sharon Kowalski was injured in a car accident, tells the story of her fight to have authority over Sharon's care and living situation after her brain injury. Kowalski's parents, to whom she had not yet come out, refused to acknowledge their relationship and took steps to prevent Thompson from visiting or having any say in their daughter's care. Their low expectations of their disabled daughter and of the rehabilitation system, combined with their disbelief and homophobia, resulted in their daughter being warehoused without the opportunity to see many of the people she loved. The book was published before Thompson successfully obtained guardianship. A powerful and descriptive narrative (Source: Center on Human Policy, Syracuse University).

Turnbull, A., & Turnbull, R. (1978). Parents speak out: Views from the other side of the two-way mirror. Columbus: C.E. Merrill.

Ann and Rud Turnbull. Parents of children with disabilities discuss their experience and lives from a number of perspectives. Recommended by Jamie Ruppman, Associate Director, The Advocacy Institute.

Walker, L.A. (1986). A loss for words: The story of deafness in a family. New York: Harper and Row.

Walker describes her experiences as the hearing child of deaf parents. While growing up, she often served as their ears and mouth, thereby living on the sometimes uneasy border between child and adult roles (Source: Ray D. Kent, <http://www.mnsu.edu/comdis/kuster2/therapy/firstperson/consumerbooks.html>).

Williams, D. (1996). Like colors to the blind. New York: Times Books.

Like Colors to the Blind 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 (Source: Center on Human Policy, Syracuse University). Recommended by Phil Smith, Assistant Professor, Special Education, Eastern Michigan University.

Williams, D. (1992). Nobody, nowhere: The extraordinary autobiography of an autistic. New York: Avon Books.

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” (Source: Center on Human Policy, Syracuse University). Recommended by Diana Lawrence-Brown, Chair, Inclusive Graduate Programs, St. Bonaventure University; and Phil Smith, Assistant Professor, Special Education, Eastern Michigan University.

Williams, D. (1994). *Somebody, somewhere: Breaking free from the world of autism*. New York: Times Books.

This autobiography by Donna Williams poignantly and defiantly illustrates her life and struggle with autism. She powerfully articulates her "awakening to the world" and how she fought for others to do the same. She presents her perspective of autism and reminds readers that it is crucial that they seek to understand her perspective and the perspectives of others with autism rather than imposing their own notions onto someone else. She asserts that she has taken control of her autism, that it does not control her (Source: Center on Human Policy, Syracuse University). Recommended by Phil Smith, Assistant Professor, Special Education, Eastern Michigan University.

Willmuth, M., & Holcomb, L. (1994). *Women with disabilities: Found voices*. Binghamton, NY: Haworth Press.

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 (Source: Center on Human Policy, Syracuse University).

Zuckoff, M. (2002). *Choosing Naia: A family's journey*. Boston: Beacon Press.

Halfway through their first pregnancy, Greg and Tierney Fairchild hear the news all expectant parents dread: their baby isn't perfect. A routine ultrasound reveals that the fetus Tierney carries has a major heart defect. Making matters worse, the nature of the defect leads doctors to suspect it might be a symptom of Down syndrome. With those events as its starting point, *Choosing Naia* examines the exploding world of prenatal information--and the emotional maelstrom that ensues from an unwanted test result--through the prism of the Fairchild family's experiences. Rapid advances in prenatal testing are enabling doctors to diagnose with great certainty a wide assortment of problems inside the womb. But that's where certainty ends. As they struggle with grief and confusion, would-be parents have only days or weeks to make choices--abortion, adoption, or continuing the pregnancy and keeping the child--whose reverberations are bound to alter the course of many lives. In the Fairchilds' case, those choices are further complicated by race. Having married across racial lines, Greg and Tierney can imagine the discrimination felt by the disabled. Ultimately, that understanding informs their decision about whether and how to parent a disabled child. Once the choice is made, they face a difficult delivery, where Tierney's vigilance literally saves her baby's life, and

high-risk open-heart surgery before the baby they name Naia can celebrate her first birthday. After clearing those hurdles, the Fairchilds face new barriers they must tear down on behalf of their beloved child for all the days of their lives (Source: Excerpted from Book Description, Amazon.com). Recommended by Deb Einhorn, Director, Family Matters, Family Support Program, Parent Training and Information Center and ARC Community Support System.

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

Basford, C. (2005). We dance together: A painted essay about my education with Katie. Seaman, OH: Author.

We Dance Together, A Painted Essay about my Education with Katie, is 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 (WeDanceTogether.com).

Baskin, A., & Fawcett, H. (2006). More than a mom: Living a full and balanced life when your child has special needs. Bethesda, MD: Woodbine House.

More than a Mom 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 (Book Description, Amazon.com). Recommended by Deborah Safarik.

Berg, E. (2006). We are all welcome here. New York: Random House.

(Fiction) As a student nurse, Paige Dunn once took care of Elvis Presley's mother in Tupelo, MS. She contracted polio while pregnant with her daughter and is paralyzed from the neck down. Deserted by her husband and on welfare, Paige relies on Peacie, her black daytime caregiver, and on her daughter, Diana, now 13, for help at night. The teen is devoted to her beautiful, talented mother, yet at times is resentful that her mother's needs must come before her own. When the girl wins \$2500 in a contest, Paige gives most of the money to Peacie for medical care for her boyfriend, who was badly beaten for participating in a civil rights demonstration. When their social worker learns that the money that would have provided for a nighttime caregiver has been used for other expenses, she demands that the situation be remedied. Diana writes to Elvis, enclosing a song her mother had written long ago, he responds with a visit to Paige, and suddenly their life is made infinitely easier. Full of humor, devoid of self-pity, with lively characters that rise above their circumstances, this is the story of an adolescent accepting

adult responsibilities, encountering the temptations of boys and booze, and experiencing the tensions between race and class in the 1960s (Source: Molly Connally, Chantilly Regional Library, Fairfax County, VA, School Library Journal, Amazon.com)
Recommended by Carol Beatty, Executive Director, The Arc of Howard County.

Biklen, D. (1993). *Communication unbound*. New York: Teacher's College Press.

Facilitated communication can open a world of communication to autistic children with other communicatively impaired individuals. This book tells about several personal experiences with facilitated communication, and about the controversy surrounding this method (Source: Adapted from Ray D. Kent, <http://www.mnsu.edu/comdis/kuster2/therapy/firstperson/consumerbooks.html>).

Blatt, B., & Kaplan, F. (1974). *Christmas in purgatory: A photographic essay on mental retardation*. Syracuse, NY: Human Policy Press.

This is a reprinted edition of Blatt and Kaplan's 1966 photographic exposé of conditions in America's institutions. Shot with a hidden camera, *Christmas in Purgatory* depicts overcrowded and dehumanizing conditions found at eight institutions in the Northeast. Blatt was one of the few professionals to speak out against institutional warehousing in the 1960s (Source: Center on Human Policy, Syracuse University).

Bogdan, R. (1988). *Freak show: Presenting human oddities for amusement and profit*. Chicago: University of Chicago.

A social history of the depiction of "human oddities," including people with disabilities, for amusement and profit, *Freak Show* is a classic study of depictions of disability in popular culture (Source: Center on Human Policy, Syracuse University).

Braddock, D. (Ed.). (2002). *Disability at the dawn of the 21st Century and the state of the states*. Washington, DC: American Association on Mental Retardation.

This fifth edition is the most extensive edition of *The State of the States* volumes. Part I explores the historical basis of disability services and includes a cross-disability empirical study of public financial support for disability. Part II presents updated state-by-state profiles, which examine programmatic structure and financing of mental retardation/developmental disabilities services. Emerging trends and issues are identified, including aging family caregivers, class action litigation with regard to waiting lists for residential services, and the growth of the Medicaid Home and Community Based Services Waiver. Part III is an in-depth comparative study of the development of institutional and community services in two states: Michigan and Illinois (Source: Center on Human Policy, Syracuse University).

Campbell, J., & Oliver, M. (1996). *Disability politics: Understanding our past, changing our future*. London and New York: Routledge.

This book uses the voices of disabled people to describe the changes in the disability sector in Britain as a result of the social movement of disabled people, particularly in the 1970s to mid 1990s. This work is regarded to be a significant contribution to history, social theory and policy, and political studies. The book clearly traces the emergence and survival of the disability movement and provides an honest evaluation of its successes and failures. It then goes on to consider possible future directions for disabled people in 21st century Britain. It is great contribution to the promotion of the understanding of the disability movement in Britain (Source: Center on Human Policy, Syracuse University).

Charlton, J. I. (1998). Nothing about us without us: Disability oppression and empowerment. Berkeley: University of California.

The author uses a disability rights standpoint to discuss the international oppression of people with disabilities. He provides a theoretical framework for understanding disability oppression not as something that has come from the attitudes of people without disabilities, but because of systems and structures of oppression from which these attitudes stem. He uses interviews with disability rights activists from around the world to back his argument (Source: Center on Human Policy, Syracuse University). Recommended by Mary Cerreto, Associate Professor of Family Medicine, Boston University.

Cole, J.S. (2002). Getting life. Louisville, KY: Advocado.

(Fiction). 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. 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 that touches on the lives of staff members of an independent living center and includes an ADAPT-like group for emphasis (Source: Steven E. Brown, Institute on Disability Culture, AdvocadoPress.org).

D'Antonio, M. (2004). The state boys rebellion. New York: Simon & Schuster.

About the boys deposited at Fernald, a state institution in Massachusetts. 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 Boyse 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. Recommendation and review by Cynthia Levine, Shrieber Clinical Services Corporation.

Davis, L. J. (2002). Bending over backwards: Disability, dismodernism & other difficult positions. New York: New York University.

This is a book of essays focusing on themes related to disability identity and Disability Studies. He notes the silence regarding disability identity versus other identities such as race, gender, or sexual orientation. He argues that instability of the disability category can be the beginning of a new way of thinking about all identity categories. As he states, "The dismodern era ushers in the concept that difference is what all of us have in common. That identity is not fixed but malleable." Essays in the book illustrate the key role that Disability Studies can play in terms of cultural criticism and theory (Source: Center on Human Policy, Syracuse University).

Dougan, T., Isbell, L., & Vyas, P. (1979). We have been there: A guidebook for parents of people with mental retardation. Salt Lake City, UT: Dougan, Isbell, & Vyas Associates.

Over 50 first person accounts of what family and community life is like with a child or adult family member with a cognitive disability. Topics examined include family holidays, support services, schools, advocacy, siblings, emotional responses and creating a community of support. Many of these vignettes are filled with raw emotion, both of tenderness and anger (Source: Center for Disabilities Studies, University of Delaware).

Edwards, K. (2006). The memory keeper's daughter. New York: Viking.

(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. They 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. Review and recommendation by Deborah Safarik.

Evans, S. (2004). Forgotten crimes: The holocaust and people with disabilities. Chicago: Ivan R. Dee Press.

A stark look at the policies and actions towards people with disabilities of the Third Reich during the 1930s. Such programs as "The Children's Killing Program" and the "T4 Adult Euthanasia" program. This sometimes unremembered step toward the larger holocaust is documented in this readable, relatively short book (Source: Center for Disability Studies, University of Delaware).

Ferguson, P. (1994). Abandoned to their fate: Social policy and practice toward severely retarded people in America, 1820-1920. Philadelphia: Temple University.

A historical study of social policy and practice toward people labeled "idiots" or "severely retarded." Ferguson examines the problem of "chronicity" and shows how people with the most severe disabilities have been and continue to be excluded from reform movements (Source: Center on Human Policy, Syracuse University).

Goode, D. (1994). A world without words: The social construction of children born deaf and blind. Philadelphia: Temple University.

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 (Source: Adapted from Temple publisher book description, Temple.edu). Recommended by Phil Smith, Assistant Professor, Special Education, Eastern Michigan University.

Greenberg, J. (1984). In this sign: The highly acclaimed novel of a family whose love and courage enable them to survive in the silent world of the deaf. New York: Henry Holt.

(Fiction) Abel and Janice Ryder begin their married life together with all the hopes and dreams of a young couple deeply in love. But before long they realize that their deafness stands as an immense barrier between them and a society that seems to work only for those who can hear. Inexperienced, ignorant, and bewildered, they leave the harsh environment of a school for the handicapped and enter the insensitive world of the hearing. Through years of debt and misunderstanding, hard and degrading work, the raising of a hearing daughter, common tragedies and joys, they learn that the remarkable tool of sign language enables them to survive and, indeed, to forge a love too powerful to be broken by the painful, extraordinary world into which they were born. In a story that spans four generations, we are witness to one family's struggle to carve a place for itself out of the tides of wealth, war, and human strivings that have swept America in this century (Source: Publisher book description, Amazon.com).

Groce, N. (1985). Everyone here spoke sign language: Hereditary deafness on Martha's Vineyard. Cambridge, MA: Harvard University.

This ethno-historical study is an excellent portrayal of community life for deaf and hearing individuals of Martha's Vineyard. The reader is presented with the history of how the deafness was brought to the island. The book allows the reader to view the typicality of the lives of Islanders who were deaf, typicality due to the community's acceptance and ability to communicate with them. This well-researched book is a must, not only for people interested in the field of disabilities, but for anyone trying to struggle with inclusion into community life (Source: Center on Human Policy, Syracuse University).

Haddon, M. (2003). The curious incident of the dog in the night-time. New York: Doubleday.

(Fiction). Christopher Boone, the autistic 15-year-old narrator of this revelatory novel, relaxes by groaning and doing math problems in his head, eats red-but not yellow or brown-foods and screams when he is touched. Strange as he may seem, other people are far more of a conundrum to him, for he lacks the intuitive "theory of mind" by which most of us sense what's going on in other people's heads. When his neighbor's poodle is killed and Christopher is falsely accused of the crime, he decides that he will take a page from Sherlock Holmes (one of his favorite characters) and track down the killer. As the mystery leads him to the secrets of his parents' broken marriage and then into an odyssey to find his place in the world, he must fall back on deductive logic to navigate the emotional complexities of a social world that remains a closed book to him (Source: Excerpted from Publisher's Weekly, Amazon.com).

Hershey, L. (various dates). Poems and tapes: On the lawn, In the way, Dreams of a different woman.

Denver, CO: Author. (Books of Poetry) and Hershey, L. The prostitutes of Nairobi, You get proud by practicing. Denver, CO: Author.

Hershey's very powerful poems are about disability rights and lesbian sexuality. Her work includes essays in a variety of periodicals as well as these books and tapes Some of the poems can be read at <http://www.cripcommentary.com/> and the booklets can be ordered at <http://www.disabilitypride.com/products.php?id=6> (Source: Center on Human Policy, Syracuse University).

Johnson, M. (2003). Make them go away: Clint Eastwood, Christopher Reeve & the case against disability rights. Louisville, KY: Advocado.

This book analyzes individual, state, and federal reactions to the Americans with Disabilities Act of 1990 (ADA). Kicking it off with the media examples of Clint Eastwood and Christopher Reeve, Mary Johnson, founder and editor of The Disability Rag and Ragged Edge magazines, ties together individual experiences, watershed cases, popular culture, and media coverage to offer a cultural and historical analysis of disability rights before and after the ADA. With an honest tone she confronts an overwhelming prejudice against people with disabilities manifest by an inexcusable inaccessibility to the world in which we all live. She describes the current state of the ADA and challenges a society that welcomes people with disabilities in theory but prevents them from living full lives in practice. "A law cannot guarantee what a culture will not give" (Source: Center on Human Policy, Syracuse University).

Linneman, D. R. (2001). Idiots: Stories about mindedness and mental retardation. New York: Peter Lang.

Personal and powerful, this collection of field notes, letters, interviews, and insight challenges us all to rethink prevailing notions of intelligence. At the forefront of this book is the concept of mental retardation. Sharing his experiences and stories with four children, Linneman confronts this socially constructed concept, pointing out the

limitations it imposes on children's lives and on adults' perception of children's potential. While the feel of this book is anecdotal, it deals well with the questionable perpetuation of oppressive assumptions of incompetence and ideas of normalcy. Linneman deconstructs the concept of mental retardation and suggests focusing on the concept of mindedness rather than embracing unhelpful labels (Source: Center on Human Policy, Syracuse University).

Linton, S. (1998). Claiming disability: Knowledge and identity. New York: New York University.

In this book, Simi Linton studies disability in relation to identity. She argues that Disability Studies must understand the meanings people make of variations in human behavior, appearance, and functioning, not simply acknowledge that these variations "exist." Linton explores the divisions society constructs between those labeled disabled and those who are not. She avoids a medicalized discussion of disability and promotes the notion that people with disabilities need to claim their identities as disabled and as contributing members to the understanding of disability as a socio-political experience (Source: Center on Human Policy, Syracuse University).

Longmore, P. K. (2003). Why I burned my book and other essays on disability. Philadelphia: Temple University.

This book is composed of a series of essays on disability scholarship and advocacy by historian Paul Longmore. The book contains an introduction and four parts. Part One, Analyses and Reconstructions, includes essays on disability history, including the League of the Physically Handicapped and the Great Depression and Activism in the 1970s and Beyond. Part Two addresses portrayals of disability in television and films. Part Three focuses on ethics and advocacy, and specifically medical decision making and physician assisted suicide. Part Four, Protests and Forecasts, includes essays on disability culture and bioethicist Peter Singer as well as an autobiographical account of experiences that led to the title of the book. Why I Burned My Book relates to the author's public protest of discriminatory and unfair Social Security Administration policies that discourage disabled people from working. The book is extremely well-written and is must reading for anyone interested in Disability Studies (Source: Center on Human Policy, Syracuse University). Recommended by Mary Cerreto, Associate Professor of Family Medicine, Boston University.

Lott, B. (1991). Jewel. New York: Washington Square Press.

(Fiction) In the backwoods of Mississippi, a land of honeysuckle and grapevine, Jewel and her husband, Leston, are truly blessed; they have five fine children. When Brenda Kay is born in 1943, Jewel gives thanks for a healthy baby, last-born and most welcome. Jewel is the story of how quickly a life can change; how, like lightning, an unforeseen event can set us on a course without reason or compass. In this story of a woman's devotion to the child who is both her burden and God's singular way of smiling on her, Bret Lott has created a mother-daughter relationship of matchless intensity and beauty,

and one of the finest, most indomitable heroines in contemporary American fiction (Source: Book Description, Amazon.com). Recommended by Deanna Pedicone, Project Coordinator, Center for Disabilities Studies, University of Delaware.

Meyer, D. (Ed.). (1997). Views from our shoes growing up with a brother or sister with special needs. (C. Pillo, Illustrations). Bethesda, MD: Woodbine House.

"I can't imagine having a plain old sister," writes Ryan Clearwater, age ten, in one of the 45 essays in *Views from Our Shoes*. Ryan and the other boys and girls whose essays are featured in this collection range in age from four to eighteen. They share their experiences as the brother or sister of someone with a disability--the good and bad aspects, as well as many thoughtful observations; they are siblings of people with a variety of special needs, including autism, cerebral palsy, developmental delays, chronic health conditions, attention deficit disorder, hydrocephalus, visual and hearing impairments, Down and Tourette syndromes. These personal tales introduce siblings to others like them, perhaps for the first time, and allow them to compare experiences (Source: WoodbineHouse.com). Recommended by Deborah Safarik.

Mooney, J. and Cole, D. (2000). Learning outside the lines: Two ivy league students with learning disabilities and ADHD give you the tools for academic success and educational revolution. New York: Fireside.

The introduction (personal histories of the authors) is great reading for parents of LD or ADHD kids, and much of it has a humorous tone that makes it equally appropriate (and approachable) for discouraged adolescents. From the terror of weekly spelling tests to the few inspiring teachers and tutors the two encountered, the tales are equal parts entertaining, poignant, and encouraging to others who may well be experiencing quite similar events. There's little discussion of what methods are right or wrong--ultimately, both authors take a fundamentally pragmatic view, and it's "right" if it worked. Including information on how to recover lost class notebooks, how to make the most of a syllabus, and "The Seven Habits of Highly Disorganized People," *Learning Outside the Lines* provides students with plenty of tools to further each reader's personal idea of success (Source: Adapted from Jill Lightner, Amazon.com).

Morris, J. (1998). Pride against prejudice: Transforming attitudes to disabilities (Reprint ed.). North Pomfret, VT: Trafalgar Square.

Morris, a disabled feminist and activist, provides a feminist analysis to the study of the experiences of women with disabilities. Basing her arguments on the feminist principle that the personal is political, Morris eloquently challenges such issues as prejudice, abortion, and the notion that people with disabilities lead lives that are not worth living. She further discusses the history of people with disabilities in institutions and under the Nazi regime. Morris also examines the meaning of disability in Western culture and the meanings of history of segregation, dependence, and an emerging independence of people with disabilities. *Pride Against Prejudice* is a commentary on political activism

and rights, and stresses the need to fight back against the prejudice, stereotypes, and oppression of an ableist culture (Source: Center on Human Policy, Syracuse University).

Perske, R. (1988). Circle of friends: People with disabilities and their friends enrich the lives of one another. Nashville, TN: Abingdon.

In this warm, sensitive collection, Robert and Martha Perske offer true stories and issues to ponder, concerning Circles of Friends -- friendships between people with disabilities and so-called normals. They show how these circles cut across age groups, generations, and races, and how the hearts and world views of everyone can be enriched. The emphasis here is on pure and simple friendship (Source: Inclusion.com).

Picoult, J. (2004). My sister's keeper: A novel. New York: Atria Books.

(Fiction) Anna is not sick, but she might as well be. By age thirteen, she has undergone countless surgeries, transfusions, and shots so that her older sister, Kate, can somehow fight the leukemia that has plagued her since childhood. The product of preimplantation genetic diagnosis, Anna was conceived as a bone marrow match for Kate -- a life and a role that she has never challenged...until now. Like most teenagers, Anna is beginning to question who she truly is. But unlike most teenagers, she has always been defined in terms of her sister -- and so Anna makes a decision that for most would be unthinkable, a decision that will tear her family apart and have perhaps fatal consequences for the sister she loves. (Source: Excerpted from Book Description, Amazon.com). Recommended by Ilka Riddle, Researcher, Center for Disabilities Studies, University of Delaware.

Rothman, D. J., & Rothman, S. M. (1984). The Willowbrook wars: A decade of struggle for social justice. New York: Harper & Row.

Documents events that occurred after court-ordered reforms of Willowbrook, an institution for people labeled mentally retarded. Rothman and Rothman followed events at Willowbrook from 1975 to 1982 in an attempt to understand social reform and its implications for people being deinstitutionalized. (Source: Center on Human Policy, Syracuse University).

Schive, K., & Klein, S. (Eds.) (2001). You will dream new dreams: Inspiring personal stories by parents of children with disabilities. New York: Kensington.

You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children with Disabilities includes pieces like "Hard Choices," on the painful decision to place a brain-damaged child in a group home, and "Getting to Know My Son," on a mother's struggle to accept and love a child with Down's syndrome. Compiled by clinical psychologist Stanley D. Klein and Kim Schive, a former editor of Exceptional Parent magazine, the book offers emotional support to disabled children's families and should help educators and health-care professionals better understand these parents' perspectives (Source: Excerpted from Publisher's Weekly, Amazon.com).

Schwarz, P. (2006). From disability to possibility: The power of inclusive classrooms. Portsmouth, NH: Heinemann.

From Disability to Possibility leads the way presenting the specific kinds of teaching, classroom practices, and support approaches that will make this new model of possibility a reality. Drawing on the stories of learners, both with and without disabilities, as well as families and teachers, Patrick Schwarz shows you not only why many current special education frameworks don't work, but also how they damage children, often for life. Then he demonstrates how possibility studies offers a meaningful, practical, and doable alternative to traditional special education practices both during the school years and after. This book illustrates, through stories of struggle and success, how creative, conscientious teachers can work with everyone involved in a student's learning to make special education work (Source: Heinemann.com).

Shapiro, J. P. (1993). No pity: People with disabilities forging a new civil rights movement. New York: Times Books.

A well-written account of the disability rights movement by a well-known journalist who was covering social issues for the U.S. News & World Report at the time of the writing of this book. It is a product of the author's research of five years which involved over 2,000 interviews with hundreds of disabled people. Written in People First language and based on the "minority model" approach, the book vividly and succinctly covers the disability rights movement primarily since the late 1960s onward leading to the passing of the Rehabilitation Act of 1973, the Education for All Handicapped Children Act (1975) and culminating in the passing of the ADA (Source: Center on Human Policy, Syracuse University). Recommended by Theresa Reborn, Parent of two young adults with disabilities, Assistant Director of Publications, Academy for Educational Development, National Dissemination Center for Children with Disabilities; Sue Swenson, Executive Director, The Arc of the United States; and Nancy Thaler, Senior Advisor and Consultant, Northwestern Management Services, Inc.

Shaw, L. (1994). Honor thy son. Nashville, TN: Abingdon.

(Fiction). You've watched "Life Goes On." Are you ready for something a little different...like a mystery? 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." "A masterful novel...a suspenseful thriller..."--Jack Klugman, actor. Veteran writer-producer Lou Shaw is best-known for his long-running TV hit, "Quincy". He is the parent of a daughter with Down syndrome (Source: SpecialNeeds.com). Recommended by Deborah Safarik.

Siegel, B., & Silverstein, S.C. (2001). "What about me?": Growing up with a developmentally disabled sibling. Cambridge, MA: Perseus.

How do families cope with the stressful aspects of raising a developmentally disabled child? There are over a million mentally impaired children in the United States, and another million children suffering from physical disorders or sensory handicaps. In *What About Me: Growing Up with a Developmentally Disabled Sibling*, Dr. Siegel, a highly regarded developmental psychologist, and Dr. Silverstein, a respected pediatrician, compassionately address the issue of living with a neurologically impaired sibling. They offer an incisive guide to the psyche of siblings who must assume difficult tasks and burdens, and approach their subject from a variety of perspectives, including a poignant first-person account by Dr. Silverstein, himself the older brother of an autistic sibling; a fascinating view from Dr. Siegel based on clinical interviews with over 1000 families of different ethnic and social and educational backgrounds and their approaches to handicaps; a compelling review of research on family factors and adjustments of the nonimpaired siblings; an analysis of family coping and defenses patterned on the Adult Children of Alcoholics model; and a helpful chapter for adult siblings on the legal aspects of becoming one's "brother's keeper" (Excerpted from Alibris.com). Recommended by Diana Lawrence-Brown, Chair, Inclusive Graduate Programs, St. Bonaventure University.

Smith, J. D. (1985). *Minds made feeble: The myth and legacy of the Kallikaks*. Austin, TX: PRO-ED.

Debunking Goddard's infamous Kallikak study that purported to show the hereditary transmission of "feble-mindedness," Smith traces members of the Kallikak family and demonstrates how facts were twisted by the eugenicists to prove their theories (Source: Center on Human Policy, Syracuse University).

Thomson, R. G. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature*. New York: Columbia University.

This book examines literary and cultural representations of physical disability, framing disability within a cultural and minority context rather than a medical one. The book examines American freak shows, as well as representations of disability in literature, including Harriet Beecher Stowe, Toni Morrison, and Audre Lorde. In a brief conclusion, the author summarizes her intent in this writing "to critique the politics of appearance that governs our interpretations of physical difference, to suggest that disability requires accommodation rather than compensation, and to shift our conception of disability from pathology to identity" (Source: Center on Human Policy, Syracuse University).

Trainer, M. (1991). *Differences in common: Straight talk on mental retardation, Down syndrome, and life*. Bethesda, MD: Woodbine House.

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 (Source: Hilma F. Cooper, Cheltenham Twp . Libs., Pa., Library Journal, Amazon.com). Recommended by Deborah Safarik.

Trueman, T. (2000). Stuck in neutral. New York: Harper Collins.

(Fiction) While this book is fiction, and closer to young adult fiction at that, it reads as a first person account. Terry Trueman's narrator is 14 year-old Shawn McDaniel who has cerebral palsy and does not speak. The story revolves around his father's belief that he must kill Shawn to "put him out of his misery" despite the obviously positive relationships between Shawn and the rest of his family. The book delves in and out of family issues and quality of life questions. Most importantly, it stresses the importance of making the least dangerous assumption and offers one example of what could be going on when we just don't know for sure (Source: Center on Human Policy, Syracuse University).

Wolfensberger, W. (1975). The origin and nature of our institutional models (Rev. ed.). Syracuse, NY: Human Policy Press.

This is an analysis of the development of and growth in institutions in the 19th and 20th centuries. The book examines institutionalization in terms of the ideas and philosophies of leaders in the field of mental retardation. This book contains the foundations for Wolfensberger's influential writings about "normalization" (Source: Center on Human Policy, Syracuse University).

For Children

Mikaelsen, B. (1998). Petey. New York: Hyperion.

(Fiction) Born in 1920 with cerebral palsy and dismissed by ignorant doctors as feeble-minded, Petey Corbin spends all but the first two years of his long life institutionalized, his world barely larger than the walls of an asylum ward or, much later, nursing home. Within those walls, further imprisoned in an uncontrollable, atrophied body, he nonetheless experiences joy and love, sorrow, loss, and triumph as intensely as anyone on the outside. Able to communicate only with rudimentary sounds and facial expressions, he makes a series of friends through the years; as a very old man in a 1990s setting, he comes into contact with Trevor, a teenager who defends the old man against a trio of bullies, and remains a loyal companion through his final illness. This is actually two books in one, as with a midstream switch in point-of-view as the story becomes Trevor's, focusing on his inner growth as he overcomes his initial disgust to become Petey's friend. Mikaelsen portrays the places in which Petey is kept in (somewhat) less horrific terms than Kate Seago did in Matthew Unstrung (1998), and surrounds him with good-hearted people (even Petey's parents are drawn sympathetically - they are plunged into poverty during his first two years by the bills his care entails). There are no accusations here, and

despite some overly sentimentalized passages, the message comes through that every being deserves care, respect, and a chance to make a difference (Source: Kirkus Reviews, Amazon.com). Recommended by Janice Fitzgerald, Executive Director, Parent to Parent of New York State.

Stuve-Bodeen, S. (2005). *The best worst brother*. (C. Fremaux, Illustrations). Bethesda, MD: Woodbine House.

Emma used to be able to make Isaac laugh. He used to let her hold him without squirming. But no more. Now Isaac spits out his food and knocks down her blocks when Emma tries to play with him. Sometimes his behavior is downright embarrassing. Emma thinks Isaac would be more fun if he'd hurry up and learn some of the sign language she and her mom are trying to teach him. His slower pace is maddening at times! *The Best Worst Brother* is an endearing and realistic look at how a relationship evolves between a typically developing older sister and her younger brother with a developmental disability. It also shows how sign language can help a child that acquires speech more slowly. As Emma is pleased to discover, Isaac can learn to sign, he just learns when he's ready (Source: WoodbineHouse.com). Recommended by Deborah Safarik.

Stuve-Bodeen, S. (1998). *We'll paint the octopus red*. (P. DeVito, Illustrations). Bethesda, MD: Woodbine House.

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 (K-3) (Source: Excerpted from Lisa Gangemi Krapp, Sousa Elementary School, Port Washington, NY, School Library Journal, Amazon.com). Recommended by Deborah Safarik.

Trueman, T. (2001). *Stuck in neutral*. New York: HarperTeen.

First-time novelist Trueman raises ethical issues about euthanasia through the relationship between 14-year-old Shawn McDaniel, who suffers from cerebral palsy, and his father. In a conversational tone, narrator Shawn explains that when he was born, a tiny blood vessel burst in his brain, leaving him unable to control any of his muscles. What no one knows is that Shawn is a "secret genius" who, while unable to communicate, remembers everything he has ever heard. His condition, which includes violent seizures, overwhelmed his father, who moved out when Shawn was three years old; the man later won a Pulitzer Prize for a poem based on his experiences as parent to a victim of C.P. Weaving together memories with present-day accounts, Shawn describes the highs and lows of his day-to-day life as well as his father's increasing fascination with euthanasia and evidence that the man is working up the courage to personally "end [Shawn's] pain." The strength of the novel lies in the father-son dynamic; the delicate

scenes between them carefully illustrate their mutual quest to understand each other (Source: Excerpted from Publisher's Weekly, Amazon.com).

Documentaries on Film and Audio

Abandoned to their Fate (1997).

Drawing from scholarly records, institutional archives, original photography, and popular media, Philip M. Ferguson traces the historical origins of the prejudice and segregation endured by people with disabilities. This 30-minute film begins in the Middle Ages and ends with today's move towards independent living and school and community inclusion. Organized in outline format with various types of media demonstrating ideas, this film is excellent for professional development, teacher training, and community awareness. For more information: <http://www.pdassoc.com/attf.html>

Autism is a World (2005).

Nominated for an Academy Award® in the short subject category. Autism is a World is from the perspective of a woman who lives with this often-misunderstood disorder. It takes the viewer into an extraordinary journey inside autism from 26-year-old Sue Rubin's perspective. Sue explains what she feels, how she relates to others, her obsessions and why her behavior can be so very different. (Source: DisabilityTraining.com). For more information: <http://www.stateart.com/productions/disabilities/autismisaworld/synopsis.asp>

Beyond Affliction (1998).

Beyond Affliction: The Disability History Project is a four hour documentary radio series about the shared experience of people with disabilities and their families since the beginning of the 19th century. This Web site includes excerpts from the Shows as well as many of the primary source documents - extended interviews, images, and texts- from which the on-air programs were developed. (Source of description and site for excerpts on RealAudio: www.npr.org/programs/disability).

Breathing Lessons (1996).

The award-winning documentary, Breathing Lessons, addresses what life as a person with a disability is like from the perspective of Mark O'Brien. O'Brien, who is a poet and journalist, is paralyzed and uses an iron lung. Through his poetry and his insightful commentary, he reflects on such issues as the meaning of life, death, sex, relationships, creativity, and religion. For more information: <http://www.pacificnews.org/marko/breathing-lessons.html>

Brother's Keeper (1992).

The lives of the Ward brothers, farmers in a rural community in upstate New York, are disrupted when the oldest brother, Bill, dies and his brother, Delbert, is accused of his murder. *Brother's Keeper* focuses on the outpouring of support Delbert received from the community. The film chronicles the events surrounding Bill's death and Delbert's trial, including the townspeople's efforts to raise funds for Delbert's defense, their support of his innocence, and their refusal to see the Ward brothers through the lens of mental retardation. For more information: <http://www.sid-ss.net/slcnys/thewards.htm>

Burton Blatt: Revisiting the Vision (1995).

Through a series of clips from various conferences and talks, viewers are able to revisit the original and inspirational words of the late Burton Blatt. Blatt discusses institutional life, reactions to his and Fred Kaplan's *Christmas in Purgatory*, the questionable notion of improving institutional life, and inclusive education. Blatt knew then what we struggle with today. He is remembered for stressing and achieving goals tied to values. His optimism, humor, and passion are central to this collection. This video is included in the media package, *Revisiting the Vision: Selected Works of Burton Blatt*, which also includes a CD-ROM containing historic photographs from *Christmas in Purgatory* and *The Family Album*. For more information: <http://thechp.syr.edu/HumanPolicyPress/>

The Color of Paradise (1999).

This Iranian film focuses on the relationships between an 8-year-old boy who is blind and his unaccepting father and caring grandmother. The boy returns home from his separate school for summer recess and viewers witness a very different boy, happy and alive, than the "bad lot" his father feels he's been dealt. Through their interactions, the film covers family issues, notions of a "healthy" child, and views of disability. Visually stunning and emotionally challenging, this is a beautiful film on several levels. For more information: <http://www.sonypictures.com/classics/colorofparadise/>

The Community Imperative (2002).

In 1979, the Center on Human Policy, under the leadership of Burton Blatt, issued *The Community Imperative*, a declaration supporting the right of all people with disabilities to community living to counter opposition to deinstitutionalization and community inclusion by well-organized groups. Today, years later, inclusion remains controversial in some states and localities. At the same time, many people with disabilities are not receiving the supports they need to live successfully in the community. This video, provided in both VHS and DVD formats, is a documentary of a conference held in Oakland, California in 2002 to revisit the values underlying *The Community Imperative*. It features segments of presentations by and interviews with several California and national leaders. It also includes clips of historical leaders Burton Blatt, Gunnar Dybwad, and Ed Roberts. Narrated by Martin Sheen, the video recounts the history of community living and describes the challenges to achieving inclusion today. For more information: <http://thechp.syr.edu/HumanPolicyPress/>

Credo for Support (1996).

This powerful 5-minute video set to music (Ennio Morricone, The Mission soundtrack) offers a series of suggestions for people who care about and support someone with a disability. It prompts viewers to question the common perceptions of disability, professionalism, and support. Designed for use in presentations, in service, staff training, and orientation programs, this video can be a provocative catalyst for a dialogue on these issues. For more information: <http://www.normemma.com/credwait.htm>

Dance Me to My Song (1998).

This Australian film and Cannes selection was written by and stars Heather Rose, a woman with cerebral palsy who uses a computer to communicate. The film features Rose's powerful exploration of sexuality, friendship, and daily support issues. This is a strong film that deals with life issues and comes highly recommended. Disability is not demonized, defined as tragedy or deficiency, focused on as something to overcome, used to teach a lesson, or any of the other common misrepresentations in film. For more information: <http://www.vertigoproductions.com.au/dance.html>

Disability Identity and Culture (no date).

This bold and controversial selection in the Tools for Change series includes the experimental documentary Disability Culture Rap. Featuring Cheryl Marie Wade, this documentary takes a fresh look at what it means to be disabled in America. Through hundreds of images and a high-energy delivery, this is disability in our own words: who we say we are. Not the usual anthropological study of disabled people as specimens, we uncover the issues that set our souls on fire: freedom of choice, disability pride, independent living, the power of language and images, sexuality, community, and the right to live with dignity. For more information: <http://www.selfadvocacy.org/Module%20Five.htm>

Ed Roberts: His Words, His Vision (2003).

This video will draw inspiration as it features excerpts from a speech delivered by Ed Roberts, considered the "father" of independent living, at a 1981 independent living conference. His words are interspersed with contemporary photographs that depict the ongoing struggle of people throughout the world for the rights and independence modeled by this visionary leader. A perfect addition to any disability history library and its' brief length facilitates use for class discussions and trainings (Source: Excerpted from DisabilityTraining.com).

Educating Peter (1992).

This Academy Award winning documentary highlights one third grade classroom's year long efforts at inclusive education. It is a rare snapshot of classroom life, this one from Blacksburg, Virginia. While the title infers a focus on Peter, a student with Down

syndrome, the film's success is in its depiction of all that goes in to this school's daily efforts at teaching all students. It will invariably raise many issues in the discussion of inclusive vs. "special" education and will be a good tool for future teachers to observe and critique. For more information:

<http://www.stateart.com/productions/disabilities/educatingpeter/>

The Eighth Day (1996).

This Belgian film (French with English subtitles) is about the relationship forged between two men as they try to find happiness and love in their lives. In addition to many other qualities, one of the men has Down syndrome. Both lead actors shared the 1996 Best Actor prize at Cannes. Though the movie falls into several traps of representing disability, it is noteworthy that Pascal Duquenne has Down syndrome considering that many actors with disabilities are still denied roles and many able-bodied actors continue to present their interpretations of characters with disabilities. For more information:

<http://us.imdb.com/Details?0116581>

The Execution of Wanda Jean (2003).

This documentary about the execution of an African-American lesbian who killed her lover explores the humanity of both the death penalty and the label of mental retardation. The claim by Wanda Jean's lawyers that she is mentally retarded and therefore unfit to be executed raises all aspects of this ongoing discussion. This personal look at Death Row, the power of labels, and the finality of the death penalty is unforgettable. For more information: <http://www.hbo.com/docs/programs/wanda/>

Extreme Court Blues (2001).

Framed in the context of the Alabama v. Garrett Supreme Court decision, this video chronicles the backlash to this decision at the University of Illinois Chicago—the formation of the National Disabled Students Union (NDSU). The video is organized speeches given by rally and NDSU organizers; the speakers consistently make comparisons between disability issues and civil rights (comparing the reaction to the Garrett decision with the SNVCC and the Deaf President Now movement). Speakers also address issues such as tokenism, the history of institutionalization, eugenics, and sterilization, federal intervention in states' rights (e.g., comparison between the Garrett decision and the Pierce veto of a federal land grant for Dix's establishment of an asylum), the Independent Living movement, Not Dead Yet, and access to the general public education curriculum for students with disabilities.

Freaks (1932).

Tod Browning's classic horror film about actual circus performers who exact revenge on a mendacious trapeze artist was shelved for years due to the controversy it created. Viewers were shocked that Browning's actors actually had disabilities and refused to be subjected to such "grotesque figures." The film deals well with notions of ableism,

beauty, and relationships. This genre film forces viewers to confront issues of normality and humanity central to Disability Studies. For more information:
<http://freaks.cinephiles.net/>

Gahanna Bill (2001).

An uncommon documentary about a middle-aged man. "Gahanna Bill" chronicles the life of Bill Withrow, a man with developmental disabilities. Living in the small suburban town of Gahanna, Ohio, Bill's unique relationship with the town, its residents and its local high school are all captured in this emotionally powerful film. Told by the people who know him best, Bill's fascinating story is an interesting look into how one man's life can be an inspiration for so many, and how someone with a disability can overcome obstacles and make an impact in their everyday life. It is a classic example of how community inclusion benefits both people with disabilities and the community they live in (Source: DisabilityTraining.com).

Going to School - Ir a la Escuela (2001).

Going To School-Ir a la Escuela tells a memorable story about inclusion, special education, and empowering children with disabilities and their parents. The film shares the daily experiences of students with disabilities who attend middle and elementary schools in Los Angeles, revealing the determination of parents to see that their children receive a quality education. The issues of respect, civil rights, and education for all children are universal and poignantly conveyed. "Highly recommended" for both undergraduate and graduate level studies and for K-12 students, parents and educators. Commissioned by the Class Member Review Committee of the Chanda Smith Consent Decree. For more information: <http://richardcohenfilms.com/GoingtoSchool.htm>

Graduating Peter (2003).

This follow-up documentary to Educating Peter picks up with Peter in middle school and highlights his journey through his final year of high school. Peter finds himself in several different places than his classmates as he ages through the school system and receives a certificate of attendance upon graduation. This film will again raise many issues around inclusive education by showcasing one school's interpretation of least restrictive environment. Key to this interpretation are definitions of disability and assumptions about potential that are central to disability studies. For more information:
http://www.hbo.com/docs/programs/graduating_peter/

Hurry Tomorrow (1975).

Hurry Tomorrow is a powerful statement about the violation of human rights of people being treated involuntarily in a state psychiatric hospital in California in 1974. The film provides a visual record of the daily lives of patients being tied down with cuffs and straps, forcibly medicated with powerful tranquilizers, reducing them to helpless zombie like states. This cinema verité classic illustrates how individuals struggle to maintain their

dignity in a dehumanized environment. The film withstood an effort to have it banned in California and instead served to help organize ex-patient groups around the country, and to initiate an investigation into patient deaths in state hospitals. For more information: http://richardcohenfilms.com/hurry_tomorrow.html

In the Land of the Deaf (1993).

This French film is a documentary about Deaf culture. It touches on many aspects and issues of Deaf culture in a way that other films have not. From an instructor in sign language to a voice teacher pushing her students to speak, from a family's love to a woman's wrongful institutionalization, and much more, this film covers much of the spectrum in a straightforward manner. For more information: <http://www.alliancefrancaise.com.hk/events/fcp25/24.html>

Johnny Got His Gun (1971).

This film based on the 1939 novel by Dalton Trumbo, written and directed by Trumbo, explores the consequences of war through the experiences of a man rendered blind, deaf, and immobile by bombing. While the hospital staff view him as helpless and worthless, he begins to piece his story together and viewers hearing his thoughts recognize the horrific dangers of assuming anyone is incompetent or without value. For more information: http://www.eufs.org.uk//films/johnny_got_his_gun.html

King Gimp (2000).

This Academy Award winning documentary featuring Dan Keplinger, an artist with cerebral palsy, is a must-see. It spans the thirteen years from his experiences in a separate "special" elementary school to his college life and the development of his artistic skills and goals. Dan's sense of humor and determination emerge as themes, as well as his struggles with inaccessibility and the tendency (during college) to be a friend but not a boyfriend. The film deals well with the problems of assuming deficiency based on body type and physical appearance. For more information: <http://www.kinggimp.com/flash.html>

Liebe Perla (1999).

This powerful documentary highlights the friendship of two women while revisiting the Nazi's treatment of people with disabilities. The women, a young disability advocate researching the treatment of little people during the Holocaust and an 80-year-old concentration camp survivor, are similar only in that they are both called short-statured. The film is in German and Hebrew with English subtitles. It is a provocative film that is best viewed with time for discussion afterwards. For more information: http://www.disabilityworld.org/07-08_01/arts/perla.shtml

Lou Brown Unplugged (2005).

Lou Brown tells stories that communicate important lessons accrued from over forty years of working on behalf of individuals with disabilities in classrooms, workplaces and courtrooms. The stories will make you laugh, cry and angry. Lou argues for the combination of integrated schooling, authentic assessment and instruction, and other rational instructional practices and individually meaningful experiences in real work settings (Source: Excerpted from DisabilityTraining.com).

The Mayor of Bedford Street (2002).

Filmmaker Elliott has been able to create a contemporary piece with Larry Selman as the centerpiece that considers the plight of adults with mental retardation who live in large urban centers. Her portrayal of Larry touches on many issues that most individuals living in the postinstitutional age must face. Larry, and many others like him, often live in near poverty with few friends and little to occupy them. Policymakers and all who view this film may better understand the realities of life today for adults with mental retardation. (Excerpted from P. Vietze and S. Holburn in *Mental Retardation*, 42(2))

Mayor of the West Side (2006).

On the verge of celebrating his Bar Mitzvah, mentally challenged 18-year-old Mark Puddington is buoyed by the constant, loving and unstinting support of his devoted mother, even as she worries about what he'll do when she's gone. An unsentimental look at the disabled, *Mayor Of The West Side*, which is Mark's nickname in the neighborhood, asks whether there is such a thing as too much love and what happens when someone is pushed to finally make it on his own. Against the backdrop of his exceptionally moving religious ceremony, Mark's family, including his father and brother, express their own concerns about his uncertain future (Source:<http://www.flatbushpictures.com/mayor.html>).

My Flesh and Blood (2003).

This 2003 Sundance Documentary Feature Audience Award winner follows a year in the life of a family of thirteen children with various disabilities headed by a single parent. Honest and touching, the film explores the definition of family while shattering many commonly held assumptions of disability as tragedy and deficiency. Central to this film is the idea that all of these kids are kids first. For more information: [http://chaikenfilms.com/Frameset\(films\).html](http://chaikenfilms.com/Frameset(films).html)

Murderball (2005).

From the gyms of middle America to the Olympic arena in Athens, Greece, *MURDERBALL* tells the story of a group of world-class athletes unlike any ever shown on screen. In addition to smashing chairs, it will smash every stereotype you ever had about the disabled. It is a film about family, revenge, honor, sex (yes, they can) and the triumph of love over loss. But most of all, it is a film about standing up, even after your

spirit - and your spine - has been crushed (Excerpted from <http://www.murderballmovie.com/about.html>).

No Apologies (1994).

This 28-minute video is by Wry Crips Disabled Women's Theatre, which is a comedy troupe of women who are at the forefront of the disability culture movement in the San Francisco Bay area. It is comprised of disabled and able-bodied women of diverse racial, social, and class background. Wry Crips uses humor as a form of resistance. Their performances, comprised of poetry, readings, signing, performing skits, and reading narratives, all resist medical paradigms, social stereotypes, economic oppression, or individualist assumptions regarding disability issues. The women of Wry Crips embrace disability, seeing beauty and acceptance where able-bodied people only see difference and abnormality. For more information: <http://www.lustydevil.com/fatgirl/wrycrips.html>

On a Roll (2005).

Greg Smith and his family bare all in this unflinching portrait of a 65-pound man striving for the American Dream. Fueled by discrimination, Smith created "On A Roll Talk Radio on Life and Disabilities" from his power wheelchair in 1992. The father of three travels the globe in a new civil rights movement, but finds his own nation's capital inaccessible - a minor challenge compared to living independently and having safe intimate relationships with facilitated sex. DVD includes interviews and special features (Source: DisabilityTraining.com).

Regular Lives (1988).

Regular Lives was produced in 1988 for PBS by the Academy Award winning directors Gerardine Wurzburg and Tom Goodwin; Syracuse University professor Douglas Biklen was its Executive Producer. The documentary explores inclusion of students with disabilities in elementary and secondary classes and includes interviews with teachers, a school principal, and parents. A concluding segment shows young adults with disabilities living on their own in their communities. Themes include the least dangerous assumption, school and community citizenship, and the value of diversity. For more information: <http://teacher.shop.pbs.org/product/index.jsp?productId=1407524>

Self-Advocacy: Freedom, Equality, and Justice for All (no date).

This award-winning video is part of the ACT series, Tools for Change. Narrated by writer, performer, and activist Cheryl Marie Wade, this program combines interviews, archival footage, and photographs to describe dominant historical models of disability and the roles self-advocates can and are now playing in determining their own lives. From the moral and medical models to the minority group model to the independent living and disability rights movements, Wade charts the course that has led to the present and offers the framework for self-advocates to continue to develop their voice and

maintain the efforts towards inclusive societies. For more information:
<http://www.selfadvocacy.com/Module%20One.htm>

Self Advocates Becoming Empowered (1997).

Self Advocates Becoming Empowered is about people with cognitive disabilities forming a national organization to work on issues they deem important, such as closing institutions, exercising their rights as citizens, supporting people to live in communities, and opposing injustice in the criminal justice system. Likening their movement to the civil rights movement of the 60s, many of the advocates speak out about the importance of their mission to people with disabilities. For more information:
http://thechp.syr.edu/HumanPolicyPress/SABE_video.html

Selling Murder: The Killing Films of The Third Reich (1991).

This is a chilling Nazi propaganda film about the genocide of people with disabilities during the Second World War. Under what the Third Reich termed the “hereditary health law,” they convinced doctors that killing people with mental or physical disabilities was for their own good, and the good of the Aryan nation at large. The original film makers used shadows and poor lighting to make people seem grotesque, and played on the medical model of disability in terms of what is “abnormal” and “normal,” and even “human” and “not human.” This is a powerful film that should generate interesting discussions if used in a Disability Studies class. Please note: This film was aired on the Discovery Channel a few years ago, and we are not sure of its availability, but it is definitely worth a good search. For more information on people with disabilities during the Holocaust:
<http://www.ushmm.org/research/library/bibliography/handicapped/right.htm#film>

Sound and Fury (2001).

This Academy Award nominee for Best Documentary follows one extended family on their journey as two sets of parents deal with the question of getting cochlear implants for their deaf children. This is an intense film that is sure to inspire excellent discussion about the nature of cures in general, but specifically around the value of the implants. The film educates viewers about Deaf culture and raises problematic societal issues around diversity, humanity, and membership that continue today. It is challenging, effective, and entertaining. For more information: <http://www.pbs.org/wnet/soundandfury/>

Taylor's Campaign (1998).

Taylor’s Campaign is a humorous and insightful look at hardworking people living in cardboard lean-tos and dumpster diving for survival in Santa Monica, California. When local lawmakers threaten to suspend their civil rights in a drive to sweep the streets of "the homeless," a destitute ex-truck driver who became disabled in an auto accident decides to run for city council on a platform of tolerance. This video has been described as "the best film on homelessness in this era...an invaluable resource for teaching about

poverty." Recommended for all age levels. For more information:
<http://richardcohenfilms.com/taylor's.html>

Titicut Follies (1967).

Although more than 30 years old, Titicut Follies remains a classic, depicting institutional life in a mental health facility. The 1967 Wiseman film is named for and centers around a talent show, the Titicut Follies, held for the inmates of the Bridgewater State Mental Hospital, in Massachusetts. While scenes from the talent show are disbursed throughout the film, the stark reality of daily life in the institution is revealed. There is little regard for the inmates' human dignity; not only is what they have to say dismissed, but they are subjected to strip searches, lack of privacy, ridicule, and isolation. Titicut Follies is a grim film that reflects the barren existence of life in a mental hospital. For more information: <http://www.zipporah.com/index.html> and <http://www.subcin.com/titicut.html>

Tools for Building a Self-Advocacy Group (2000).

This instructional video presents specific steps and tools for building a self-advocacy group. Part of the Self-Advocacy Start-Up Toolkit developed by Self Advocates Becoming Empowered (SABE), it includes the philosophy of self-advocacy and challenges viewers to work to make it happen in their lives. The start-up process is broken into five sections: Starting Groups, Working on Issues, Self-Advocates and Self-Determination, Advisor Issues, and Materials on The Self-Advocacy Movement. For more information on the Toolkit: <http://thechp.syr.edu/HumanPolicyPress/toolkit.html>

Twitch and Shout (1995).

This is a must-see documentary about living with Tourette Syndrome (TS) made by photojournalist Lowell Handler who has TS himself. The film explores what TS is, what it means to live with it, and people's reactions to the tics that are its physical manifestation. TS is reclaimed and reframed in terms of life energy. Handler calls out notions of normality as he weaves together the immediately appealing stories of four successful adults. The film should challenge viewers to rethink notions of human value and individual differences. For more information <http://www.blinddogfilms.com/twitchandshout/>

Vital Signs: Crip Culture Talks Back (1997).

In the documentary Vital Signs: Crip Culture Talks Back, participants in a national Disability and the Arts conference explore the politics of disability through their performances, which include such texts as art, fiction, poetry, stand-up comedy, drama, and personal stories. It features such disability rights activists as Cheryl Marie Wade, Mary Duffy, and Harlan Hahn, and also includes group debates and behind-the-scenes conversations. The film also addresses the culture of disability and the shared struggle

people with disability have in gaining access to influential cultural institutions. For more information: http://www.fanlight.com/catalog/films/230_vs.shtml

What Does Normal Mean? (2006).

“What Does Normal Mean” is a compelling documentary film about the “inclusion” of children with disabilities in public schools. The film follows seven children – elementary to high-schoolers – with a broad range of disabilities, over an academic year. Produced by multiple Emmy award winning filmmakers, the children’s struggles and triumphs give dramatically clear testimony to the value of equal educational opportunities for all. The documentary is constructed so that each child’s story can be viewed and discussed as a chapter, generating many different teaching and learning issues. Excellent for college students, community programs, advocacy or parent groups, or anyone that wants to see and “feel” how an inclusive change in our schools has made us more aware and thoughtful about potential, difference and about what normal means (Source: DisabilityTraining.com)

When Billy Broke his Head... And Other Tales of Wonder (1995).

First premiering on PBS in 1995, this film by Billy Golfus explores the concept of disability rights and takes a close look at the disability rights movement and those involved. Golfus, who has a traumatic brain injury, intertwines his story with the experiences of others who are struggling for their rights. This is a must see. For more information: http://www.fanlight.com/catalog/films/136_wbbhh.shtml

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