

Autobiographies/Personal Accounts

Ashby, C., & Causton-Theoharis, J. (2009). Disqualified in the human race: a close reading of individuals identified as autistic. *International Journal of Inclusive Education*, 13(5), 501-516.

The authors use autobiographies of individuals identified as autistic to explore how these individuals address issues of competence. The authors focus on how these adults and adolescents discuss their own notions of competence, and supports and practice that allow them to demonstrate their competence.

Alatalo, T. (1999). *Olen ja saan sanoa. Helsinki: Werner Soderstrom Osakeyhtio oyj.*

A Finnish young man's autobiographical account. He uses facilitation to communicate.

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

Includes explanations of behavior considered challenging by Sean Barron himself, a young man with the label of autism. The combination of accounts by Sean and his mother, Judy, provide a full family account.

Biklen, D. & Burke, J. (2006). Presuming competence. *Equity & Excellence in Education*, 39, 166-175.

"At least since the early 1990s, educators in inclusive schooling as well as scholars in Disability Studies have critiqued prevailing notions of intellectual ability and have suggested the importance of interpretive communities for constructing student competence. This work follows the tradition of education-as-dialouge, which some have argued in a sine qua non for conceptualizing education with individuals who have been traditionally marginalized" (p. 166).

Biklen, D. (Ed). (2005). *Autism and the myth of the person alone. New York: New York University Press.*

Edited by Biklen, with chapters written by Richard Attfield, Larry Bissonnette, Lucy Blackman, Jamie Burke, Alberto Frugone, Tito Rajarshi Mukhopadhyay, and Sue Rubin, this book challenges the prevailing, tragic narrative of impairment that so often characterizes discussions about autism. "A basic premise of the book is that people classified as autistic, even those who cannot speak, are thinking people with ideas about their lives and their relationship to the world. I call this orientation the presumption of competence" (p. 1).

Biklen, D., & Duchan, J. (1994). "I am intelligent": The social construction of mental retardation. *The Journal of the Association for Persons with Severe Handicaps*, 19, 173-184.

This article challenges the usefulness and validity of the label of mental retardation by offering first-hand accounts of those once considered retarded now communicating their intelligence.

Biklen, D., & Rossetti, Z. (producers) (2005). *My classic life as an artist: A portrait of Larry Bissonnette. Video documentary. Available from Syracuse University, 370 Huntington Hall, Syracuse, New York.*

Looking back on his years of living in a closed institution for people labeled mentally retarded, Vermont-based autistic artist Larry Bissonnette assesses this form of "apartheid" as "better for

growing vegetables rather than people." This documentary is filled with Bissonnette's humorous yet poignant assessments of his life – growing up, his family, and creating art. Moving back and forth between speech, typing, and painting, Bissonnette's wit and insight punctuate a day in the life of this Outsider artist, and artfully illustrate the complexities of expression.

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

Lucy Blackman was at one time thought moderately retarded (actually in Australia the term applied was intellectually disabled). She learned to communicate using facilitated communication and has since graduated to being able to type without physical support. She earned a bachelor's degree in arts and letters from Deakin University in Australia and is currently enrolled in graduate studies. Anthony Attwood says of Blackman's book in his introduction: "Lucy provides the point of view of someone with autism who has never used speech. I first met Lucy in Melbourne in 1990 and over the intervening years she has taught me more about autism than any academic text" (p. vii).

Bogdan, R., & Taylor, S. (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 inmates of institutions for people labeled retarded. The authors argue that mental retardation is not a real entity, but rather a social construction.

Broderick, A., & Kasa-Hendrickson, C. (2006). "I am thinking that speech is asinine": Narrating complexities and rethinking the notion of "independence" in communication. *Equity & Excellence in Education*, 39, 176-186.

The authors interrogate their positionality as researchers and how they are situated within their research. They also provide narratives of FC users and how these FC users negotiate their identities and their use of typing and speech.

Broderick, A., & Ne'eman, A. (2008). *Autism as metaphor: Narrative and counter-narrative. International Journal of Inclusive Education*, 12 (5-6), 459-476.

The authors explore the significance of metaphor and dominant cultural narratives of autism. They explore the current struggle around autism as a metaphor for disease versus autism within neurodiversity. The authors argue that the current dominant discourse as autism as a metaphor for disease creates misunderstandings about the causes of autism and interventions for autism.

Broderick, A. (2009). "Autism," "recovery [to normalcy]," and the politics of hope. *Intellectual and Developmental Disability*, 47(4), 263-281.

The author uses critical discourse analysis as a method of inquiry into the concepts of "hope", "recovery" and "normalcy" as they relate to Applied Behavior Analysis and Individuals with autism.

Crossley, R., & McDonald, A. (1984). *Annie's Coming Out*. New York: Viking Penguin.

An autobiographical account of Anne McDonald's struggle to leave a mental retardation institution. McDonald, who learned to communicate via facilitation, had to pass several validation tests before being declared competent and permitted to leave the institution. "Unless

someone makes a jump by going outside the handicapped person's previous stage of communication, there is no way the speechless person can do so. Failure is no crime. Failure to give someone the benefit of the doubt is" (p. 76).

Eastham, M. (1992). *Silent words*. Ottawa: Oliver Pate.

A mother's account of how her son learned to communicate with facilitation and to become an independent typist. Includes poetry of David Eastham written prior to his untimely death. This is one of several instances internationally where facilitated communication was discovered, independent of similar discoveries in other countries.

Gillingham, G., & McClennen, S. (2003). *Sharing our wisdom: A collection of presentations by people within the autism spectrum*. North Plymouth, MA: The Autism National Committee.

This book of 22 conference presentations, accompanied by author biographies and photos, gives an insider's view of living with an autism spectrum label.

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

An autobiography by Temple Grandin about her life with autism, including accounts of her experiences as a child before people knew she could understand them, when she could communicate through speech. This is not a book about facilitation, but it is nevertheless important to understanding facilitation, for many of her experiences parallel those reported by people who now use facilitation.

Grandin, T. (1995). *Thinking in pictures and other reports from my life with autism*. New York: Vintage Books.

Thinking In Pictures is about the childhood and development of Temple Grandin, a woman with autism. 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 be closely related.

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

Charles 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 through both Charles' and his mother's narratives. When he was a child, Hale was diagnosed as "trainably mentally retarded," and it was not until he began using FC that he discovered he was autistic. While some of Charles' narrative has been edited for easier reading, the authors make a conscious choice to leave many of Charles' passages as originally typed, so that reader can see the clear intended meaning through errors made while using the method. 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."

Jackson, L. (2002). *Freaks, geeks, and Asperger syndrome: A user guide to adolescence*. Philadelphia, PA: Jessica Kingsley.

Described as a book for adolescents with Asperger syndrome by a 13-year old with a diagnosis of Asperger syndrome, this conversational account offers a strong insider's account of living with AS. Jackson discusses social interactions, bullying, fascinations and fixations, dating, friendship, sensory issues, and much more. "I have what some people would call a disability but I call a gift- Asperger Syndrome (AS)" (p. 19).

Kochmeister, S.J. (1994). *Reflections on a year of turmoil and growth*. *Facilitated Communication Digest*, 2, (4), 6-8.

An account by a person who was once presumed severely retarded and who since learned to communicate with facilitation before progressing to the point where she can type without any physical support.

Martin, R. (1994). *Out of silence: A journey into language*. NY: Henry Holt and Company.

A popular book that recounts the author's nephew's introduction to facilitated communication and his subsequent experiences. This book, favorably reviewed in the New York Times Book Review and other major media outlets, concerns theories about literacy as well as the struggles of the author's nephew to find a means of communicating.

Mukhopadhyay, T.R. (2008). *How can I talk if my lips don't move: Inside my autistic mind*. New York: Arcade Publishing.

Mukhopadhyay, an adolescent with autism whose mother taught him to read and write, lets us into his everyday life.

Mukhopadhyay, T.R. (2007). *The mind tree*. New York: Riverhead Trade.

"Eloquent. Philosophical. Introspective. These are not the words usually associated with an autistic child. But in a remarkable display of courage and creativity, a boy named Tito has shattered stereotypes, and in *The Mind Tree* makes us question all of our previous assumptions about autism. For Tito is severely autistic and nearly nonverbal, and this is his story" (www.amazon.com).

Mukhopadhyay, T.R. (2000). *Beyond the silence: My life, the world and autism*. London: National Autistic Society.

An autobiographical account by a young man with autism who learned to communicate with physical support and who now types independently and can speak. Lorna Wing has written in the forward to this book: "His writing provides a vivid description of what it is like to be autistic and his thoughts about the meaning of life. It is essential reading for anyone wanting to understand the nature of autism" (p. 3).

Nolan, C. (1987). *Under the eye of the clock*. New York: St. Martins Press.

A best-selling autobiographical novel by a writer with cerebral palsy, including a brief description of his writing method that includes facilitation.

Prince-Hughes, D. (2002). *Aquamarine blue 5: Personal stories of college students with autism*. Athens: Swallow Press.

Prince-Hughes, a woman with Asperger syndrome, edits this book of stories detailing the experiences of college students with autism spectrum labels. Many of the stories describe individuals emerging from earlier difficulties during secondary and elementary education once in college due to the development of academic, social, and sensory supports.

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

“This is a book about autism. Specifically, it is about my autism, which is both like and unlike other people’s autism. But just as much, it is a story about how I emerged from the darkness of it into the beauty of it” (p. 1).

Rice, N. (Producer), Coffey, N. (Director), Biklen, D. (Executive Director). (1999). *Sharisa: My Life as a Pioneer [Documentary]*. United States: Syracuse University Facilitated Communication Institute.

This video chronicles Sharisa’s journey to independent typing and provides information on the practice of facilitated communication.

Rossetti, Z., Ashby, C., Arndt, K., Chadwick, M., & Kasahara, M. (2008). “I like others to not try to fix me”: Agency, independence, and autism. *Intellectual and Developmental Disabilities*, 46, 364-375.

This article is about interpreting the actions or performances of individuals labeled with autism who type to communicate. More specifically, the authors discuss viewing competence amid behaviors and actions traditionally linked with incompetence. Researchers engaged in participant observation and conducted open-ended interviews with 9 participants who were working to develop independent typing skills. Three findings emerged from this research. First, participants shaped a notion of independence that included dependence on various supports. Second, researchers recognized the concept of agency in the interactions between participants and their communication facilitators. Third, participants exercised control of their lives through these expressions of agency.

Rubin, S., Biklen, D., Kasa-Hendrickson, C., Kluth, P., Cardinal, D.N., & Broderick, A. (2001). *Independence, participation, and the meaning of intellectual ability. Disability and Society*, 16, 415-429.

“When I was in school autistic people like me were usually placed in separate schools or special day classes with other disabled students (and) were not allowed to learn academic subjects. Because of the way we move and our lack of speech we were assumed to be retarded. I was thought to be retarded (but) all this changed ... once I could type without support... My very existence challenged beliefs about mental retardation. Able to type independently... my presentations (at conferences) were acts of advocacy.... When people see me they are forced to admit that their assumptions about mental retardation were wrong” (p. 419).

Savarese, R. (2007). *Reasonable People*. New York: Other Press.

The story of a Grinnell College professor, Savarese, and his adopted son DJ. Savarese describes DJ’s communication development and larger disability rights issues. DJ utilizes facilitated

communication to express his thoughts and feelings. This is also a story of inclusion and the families fight to include DJ in general education classrooms.

Schneiderman, H. (1994). Letter to the editor: Personal experiences with facilitative communication. *Journal of Child Neurology*, 9(3), 339-340.

A father/pediatrician recounts his own experiences in being a facilitator for his son and the conversations they have had together. Includes some fascinating uses of archaic expressions by the author's son.

Schubert, A. (1997). "I want to talk like everyone": On the use of multiple means of communication. *Mental Retardation*, 35, 347-354.

" This qualitative case study is a description of a young man with autism who communicated using speech, sign language, facilitated communication, body language, and his mother's conversational supports" (p. 347).

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

An autobiographical account of one person learning to communicate via facilitation. Exceptionally rich material on how Sellin experiences autism.

Shore, S. (2001). Beyond the wall: Personal experiences with autism and Asperger syndrome. Shawnee Mission, KS: Autism Asperger Publishing.

This comprehensive autobiography follows Shore from birth through his marriage and professional career as an advocate, educator, and doctoral student. He blends a researcher's perspective into this account as he analyzes his experiences via some of the literature on autism.

Sienkiewicz-Mercer, R. & Kaplan, S. B. (1989). I raise my eyes to say yes. Boston: Houghton Mifflin.

Not about facilitation, but this book is a very well written account of communication with augmentative and alternative systems, demonstrating the importance of interaction between the person doing the communicating and a communication partner.

Wurzburg, G. (producer/director) (2004). Autism is a world. Documentary. Atlanta: CNN.

For 26 years, Sue Rubin has been on an extraordinary journey. Her unusual behavior led to a diagnosis of autism when she was four. She was believed to be retarded until age 13. But then a new communication technique, facilitated communication, gave Sue the ability to connect with the world. Now, she is a junior in college with a top IQ, a tireless disabled-rights activist, and an articulate guide into a complex disorder. The documentary film was nominated for an Academy Award.

Zoeller, D. (1992). Ich gebe nichtauf (I won't give up). Bern: Scherz Verlag.

Autobiographical account of life with autism, written by a person who uses facilitation. Includes useful insights into difficulties with dyspraxia.