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## Feisty Stories of Living with Disability

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## Feisty Stories of Living with Disability

Scot Danforth

Carol Rogers-Shaw's rich memoir continues a fascinating tradition of autobiographical disability narratives that include works such as Stephen Kuusisto's (1998) *Planet of the Blind*, Terry Galloway's (2009) *Mean, Little, Deaf Queer*, Meri Nana-Ama Danquah's (1998) *Willow Weep for Me*, and disability rights leader Judy Heumann's (2020) *Being Heumann*. These exemplify what Garland-Thomson (2007) called "fresh and feisty disability narratives" (p. 119). Without apology, and often with great pride, these stories place the impaired and vulnerable body at the center of the plot structure. Through her own narrated experiences and by weaving in myriad encounters with her many disabled students, Rogers-Shaw skillfully recasts the stale tradition of tragedy-to-cure plots into full, authentic explorations of humans contending with precarity. The tales are deeply human, dealing with despair, hardship, connection, and joy. Her stories are truly a gift.

But any examination of Rogers-Shaw's autobiographic writings must first contend with the elephant in the room, the dominant narrative of disability. Even the feistiest and freshest disability narrative does not issue forth into a welcoming cultural space waiting for honest explorations of human experience. It inevitably bumps full force into the dominant tale that already occupies that space, the American disability mythology that fills our pervasive assumptions about what it means to have a disability. I am referring to the ubiquitous Overcoming Disability story.

For modern Americans, the archetypal hero of the Overcoming Disability story is Franklin Delano Roosevelt. In the 20th century, as the professional fields of rehabilitation, special education, psychology, and psychiatry gained scientific and practical credibility, and non-disabled experts on disability predominated in those professions, the overarching tale of FDR "overcoming" his polio pervaded the cultural landscape. Our moral imagination of what disability means, the import of these helping professions, and what disabled people should be doing were carved deep into our unconscious minds by the powerful story of FDR overcoming his disability.

The story goes like this: FDR contracted polio in August 1921 at age 39, leaving his legs paralyzed. The political aspirations of the talented, wealthy cousin of President Theodore Roosevelt seemed doomed by this tragedy (Oshinsky, 2005; Smith, 1990). But FDR discovered the healing waters of a tumbledown resort in rural Warm Springs, Georgia. There he worked with physicians and rehabilitation experts to develop a water exercise program that, through his hard work and endless determination, put him back on his feet. He reappeared dramatically on the political stage, walking slowly and with tremendous effort to the podium to make inspirational speeches at the 1924 and 1928 Democratic Conventions. He became president in 1932 and successfully steered the nation through the darkest days of the Great Depression. A man who had defeated evil polio had the strength and courage to guide the country through the most difficult challenges (Harmon, 2014; Lippman, 1977; Oshinsky, 2005; Walker, 1953).

For Americans, the FDR story bolsters five specific, oft-unquestioned “truths” about disability. First, disability is a personal tragedy that assaults the body and reduces a person to a lesser version of humanity. Second, a disabled person might recover, regaining functioning and full humanity, by working under the guidance of professional experts. Third, such a recovery requires intensive hard work. The Protestant work ethic is central to the field of rehabilitation. A person hoping to recover must earn their recovery.

Fourth, disabled people who overcome their disabilities provide a service to all persons by being inspirational. From FDR to the computer-generated “walking” Christopher Reeve of the 2000 Super Bowl commercial to, more recently, musician Kodi Lee on *America’s Got Talent*, disabled people who beat the odds (i.e., beat their disability) inspire us.

And finally, the fifth truth is that the problem of disability is not political. The Overcoming Disability story does not involve a misunderstood, maligned, minoritized group fighting back from the margins of society. The problem is... well, go back to the first truth: disability is an individual tragedy to be overcome on a personal basis.

Salient for educators is the unfortunate centrality of this Overcoming Disability story in the field of American special education. The field was built as a scientific enterprise and a venture of school-based interventions on the foundation of this dominant cultural narrative. Students with disabilities who succeed do so because they embrace a stringent work ethic and because the profession of special education avails them of evidence-based interventions—scientific curatives that help them function more like their non-disabled peers.

One way of understanding the decades of debates about the effectiveness, feasibility, and ethics of inclusive education is by noticing how inclusion confuses the Overcoming Disability story. How can a person with a disability simply live and learn fully within mainstream society without first traveling a road of recovery? What about the hard work and effort required to improve a disabled person’s functioning? What about the effective interventions provided by science-backed professionals? How can we simply skip all that to foster a diverse learning community that accepts and supports students of varying bodies and minds? Viewed through the dominant cultural narrative of Overcoming, inclusion seems like a fictional, dishonest shortcut.

Inclusive education, disability rights, and feisty and fresh stories like Rogers-Shaw’s tales of precarity forward a different cultural narrative. In these accounts, disability is not viewed as a medical tragedy to be overcome through hard work and evidence-based interventions, but as human experience in a politically cruel world. As explorations of human experience, these stories grant legitimacy to the endless natural variations of the body, illuminating the ways that bodies are aspects of human fulfillment, frustration, risk, and hope. As narratives of a politically cruel world, they shine light on the many attitudinal and institutional obstacles that block disabled people’s access to participation and fulfillment. These stories are feisty because disabled people have to, in Rogers-Shaw’s words, “keep on fighting.”

As we pay close attention to authentic disability stories, listening deeply, we should also acknowledge the truthful historical narrative hidden behind the popularized FDR mythology. Gallagher's (1985) wonderful book, *FDR's Splendid Deception*, written by the disabled man who almost singlehandedly created the 1968 Architectural Barriers Act, tells the story of Roosevelt's extensive efforts to hide his impairment and his wheelchair to create the illusion of "overcoming." The White House Press Corps worked closely with FDR to craft a mythical image of physical strength because they thought a struggling nation needed a non-disabled leader. In truth, FDR never regained any ability to walk.

FDR didn't find healing waters in Warm Springs, Georgia. But he did find magic, a supportive community of people with physical disabilities, a safe space defended against the stigmatizing norms of the outside world. People with polio or other physical impairments came from across the United States to join the accepting community. "It was the only place where Roosevelt could truly be himself, surrounded by those who loved and suffered as he did, and dreamed the same dreams. There was nothing to hide from the polios, no reason to deceive" (Oshinsky, 2005, p. 39). FDR "could move from pool to lawn by crawling on his belly like a walrus" (Smith, 1990, p. 60). He and his friends could stumble and fall down without embarrassment. They shared picnics, card games, late afternoon drinks, festive dinners, and after-dinner sing-alongs (Smith, 1990; Stevens, 1947; Walker, 1953). Lives of precarity—both physical and social—were lives well lived as the disabled community members fashioned friendship and fun together.

The numerous accounts of FDR's hidden life in the Warm Springs disability community provide us with the same stuff Rogers-Shaw gifts us in her stories: comforting and troubling insights into the fullness of lives lived against the cultural grain, lives carried by bodies wavering on a windy high wire, lives of love and goodness and sadness. Rogers-Shaw invites educators to explore and appreciate the reasons why many of us became teachers in the first place. If you are like me, you hoped to sink yourself into the uncertain marrow of humanity, the deepest and fullest and most varied experiences available. You hoped to live and learn and grow in that richness. With her stories, Rogers-Shaw brings us to these depths, and we are better for it.

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**Scot Danforth** is professor of disability studies and inclusive education at Chapman University. His books include *Becoming a Great Inclusive Educator* and *The Incomplete Child: An Intellectual History of Learning Disabilities*. His current research focuses on the life and influence of the great disability rights leader Ed Roberts.