

Book Review: They Created Us

Contributed by Daniel Werges

Book review of *They Created Us*, by Denise Mercado, reviewed by Daniel Werges.

Mercado, D. (2006). *They Created Us: Special Education, Medicaid Waivers, EPSDT, Independent Case Management—A Family's Journey Through a Bureaucratic Maze!* Bloomington, IN: Author House. 315 pages, \$19.95 paperback

They Created Us reads like a David and Goliath story of a mother's fight to receive vitally needed services for her severely disabled son. Author Denise Mercado's six-month-old son, Danny, fell ill with a rare form of meningitis that resulted in severe developmental disabilities and life-long medical conditions. After 11 years of caring for her son single-handedly and being told repeatedly, including by social workers, that her family's income was too high to receive public support, Denise was at a breaking point. The stress of caring for Danny and two other children and worrying about the debt incurred to cover his medical care had taken its toll. {mosgoogle right}

Fortunately, Denise had the opportunity to participate in a life-changing training course for people with disabilities and their parents. The program enlightened her about the rights of disabled people, self-advocacy, inclusion, and the use of the legislative process to challenge slow-moving bureaucracies.

During one of the training sessions, other parents informed Denise about the Home and Community Based Services waiver system, which allows Medicaid-funded supports to be provided in the community instead of in an institutional setting. Denise was furious that she had been kept in the dark about services Danny had been entitled to all of his life.

Once she understood her son's rights, Denise was unstoppable. She challenged bureaucratic systems until her son received inclusive education in the neighborhood school and support services at home. Denise fought battle after battle to not only improve the quality of her son's life, but also to advocate and campaign for those in similar situations. She went back to college to complete her education, formed a local advocacy group, served as manager and director of disability organizations, and co-founded a Medicaid provider agency that gives individuals with disabilities and their parents more control over the services provided.

Denise's moving story speaks of her faith, the loving support of her husband, the power of community organizing, and most importantly of her infinite love for Danny.

Although the book goes into many details specific to North Carolina, it will be a welcome resource for parents of children with disabilities who continue to fight for the implementation of inclusive education and disability rights legislation. Denise's story can also serve as an inspiration for social work students to explore the often unpopular intellectual and developmental disabilities field.

Social work educators can use excerpts to illustrate the importance of the strength perspective, resilience theory, spiritual assessments, and community organizing. Although some social workers will object to the book's contention that professionals often do not know what is best for a disabled child, it can serve as a tool to explore strained relationships between consumers and professionals.

They Created Us has challenged me personally to question my part in the disabling bureaucracy. It is also my belief that the social work profession needs to rethink how much enabling support can be given with the current focus on individual and medical models of disability. This parent narrative underlines the importance for social workers to partner with parent advocates, the disability rights movement, and disability studies to contribute to fighting disability discrimination on all levels.

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