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Awakening to Disability: Nothing About Us Without Us by Karen Stone

Reviewed by Connie Valentine, MS

In addition to being witty, readable, and filled with helpful information, Karen Stone's book, *Awakening to Disability* is important for physicians and health caregivers for three main reasons:

- It introduces in a very human way the disability community, which includes patients, acquaintances, friends, strangers, clients, and relatives.
- The tenuousness of life. You could join that community this evening on your commute home. We can and should prepare for such an event.
- You or someone close to you may already have a significant disability.

Ms Stone normalizes the world of disabilities. She bursts myths and lets us know what we are afraid to know: people with disabilities are the same as people without. She confronts prejudice and reduces anxiety with practical ways to overcome barriers of fear and awkwardness. The best part is that she makes us laugh while doing all this.

You'll learn the nuances of language: the correct term is *a person with a disability*.

You'll learn the nuances of etiquette: it is not appropriate to touch a wheelchair or guide dog. It is important to sit when talking with someone who is sitting.

You'll learn the nuances of architecture: an inch may be a mile for a person navigating a wheelchair over a strip of wood nailed to the floor or across a lush, thick carpet.

You'll learn the nuances of attitude: the author skewers those who refer to the person with a disability as if s/he were not present.

Ms Stone shares just enough research, alerting us that at least 20% of the population have some level of disability; most live in poverty.^{1:p4} She describes Denmark's brilliant cost-cutting decision to replace nursing homes with government-subsidized mixed living complexes and the Swedish housing policy, requiring new construction to pay special regard to the needs of people with physical disabilities and the elderly. She also describes Vancouver, Canada's successful experiment with separate accessible transportation. Most people need accessible homes and transportation at some point.

Your patients will also benefit from this book, which illuminates the deep emotions of grief and loss experienced by people with disabilities. It gives a context for the importance of collaborative medical care in which shared decision making empowers and engenders cooperation. It describes the disability rights movement and such heroes as Ed Roberts who moved mountains by refusing to take "No" for an answer. Spending lonely nights in University Hospital in an iron lung, he received his PhD from the University of California at Berkeley despite initially being turned away. He became director of the California Department of Rehabilitation in 1975 and is considered by many to be the Martin Luther King, Jr of the disability rights movement.

Some topics covered in this wide-ranging treatise on disabilities are: diet and exercise, education, jobs, attendant care, money, nursing homes, and suicide.

Ms Stone describes the solitary journey each person travels into the unknown territory of disability. As her own neurologic disability progressed, her once physically active life slid slowly to a halt, but her life as a journalist blossomed. She writes primarily about coping with physical disabilities, but devotes space

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to abuse of people with disabilities and "invisible disabilities" including mental illness.

She puzzles over causes of mental illness, describing her own fierce depression that led to a suicide attempt as she awakened to her disability. I had puzzled over these symptoms too. I contacted Ms Stone to discuss new research from the Adverse Childhood Experiences Study by Kaiser Permanente and the Centers for Disease Control and Prevention that helped me understand the origin of depression. Without hesitation, she welcomed me as a friend and colleague. You will probably consider her a friend and colleague too, after reading *Awakening to Disability*. ♦

Reference

- Stone KG. *Awakening to Disability: Nothing about us without us*. Volcano (CA):1997.

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