

Book Review

Title: *Aidan's Way: the Story of a Boy's Life and a Father's Journey*

Author: Sam Crane

Publisher: Sourcebooks, Inc., 2003

ISBN: 1-57071-903-9

Cost: \$18.95 USD

Title: *A Will of His Own: Reflections on Parenting a Child with Autism*

Author: Kelly Harland

Publisher: Woodbine House, 2002

ISBN: 1-890627-19-4

Cost: \$16.95 USD

Title: *Karen*

Author: Marie Killilea

Publisher: Dell Publishing Company, Inc., 1952

ISBN: 1568490984

Cost: \$25.25 USD

Reviewer: Fred Pelka

“I don't believe that cerebral palsy children have any mentality.”

So spoke a leading physician of his day, a specialist whom the Killilea family consulted in the late 1940s to determine the best treatment for their daughter, Karen. It was in large part to challenge such abysmal ignorance, such stunning arrogance, that Marie Killilea wrote her memoir, *Karen*, published in 1952. The book was a breakthrough in educating the general public about the nature of CP, and the real (as opposed to the mythic) struggles of families with disabled children. Along with a series of other memoirs, it also rallied parents to join what were then fledgling organizations such as United Cerebral Palsy Associations and the ARC. Shunned by their neighbors, patronized by the medical establishment, and all but ignored by local governments refusing to educate their children, these parents would in time be largely responsible for

some of the most significant victories claimed by the disability rights movement: *PARC v. Pennsylvania*, the first recognition by US federal courts of the right of children with disabilities to a public school education; the Individuals with Disabilities Education Act; and the deinstitutionalization movement of the 1970s.

Now a new generation of parents are writing their stories, separated from Killilea by half a century and the advent of the modern disability rights movement. Two of these memoirs, *A Will of His Own: Reflections on Parenting a Child with Autism*, by Kelly Harland, and *Aidan's Way: The Story of a Boy's Life and a Father's Journey*, by Sam Crane, show both the impact and the limits of that progress.

Take, for instance, de-institutionalization. The Killilea family was urged to send Karen to an institution, which in the 1940s generally meant a "state school" such as Willowbrook or Pennhurst, massive residential facilities notorious for their squalor, neglect, and abuse. Deinstitutionalization may have freed tens of thousands, but the urge to separate disabled children from their parents remains. Having been told that Aidan's diagnosis ("Agenesis of the corpus callosum") means the boy will never walk, talk, or see, he will be "severely mentally retarded" and prone to seizures, the Cranes are urged to consider "putting Aidan away in an institution." "I was stunned," Sam Crane writes, "By how quickly some could conclude that my son, not yet a year old, was hopeless, his life lost, and that he should be excluded from the love of his family and friends" (Crane, 65). Crane confronts this dismissal of his son's worth in many guises, from the professional colleague who advises him it would be more "merciful" to let Aidan die, to the insurance company physician who rules Aidan's only food source, a prescription formula delivered through a g-j tube, is "supplemental" and thus not covered by the HMO. Crane wins this particular battle, but notes how a family with fewer resources might have succumbed to this blatant attempt to cut costs at the expense of the life of a disabled child.

"It's not just money that distorts our view of human worth," Crane notes. "Social status, cultural attainment, physical beauty: all of these and more creep into our calculations of an individual's value" (Crane, 249). Crane catches himself as much influenced by the myths of disability as those around him. He and his wife are at first willing to sign a DNR (Do Not Resuscitate) order recommended by their hospital, should Aidan need to use a ventilator. They rescind the order only after being confronted by a physician who tells them that being ventilator dependent is not the-fate-worse-than-death they assumed it to be. It's one measure of the movement's progress, and a demonstration of the rightness of the slogan "Nothing about us, without us," that this particular physician happened to have CP. (If being able to survive medical school is any indication, it would seem that people with CP "have a mentality" after all).

Sam Crane, like Marie Killilea, has written a straightforward narrative, beginning at Aidan's birth and moving along more or less chronologically. Harland's book, by contrast, is a collection of essays, or "reflections." She prefaces these with an extended quote from nature poet Mary Oliver, with whom she shares both style and outlook. For Oliver, "What I write begins and ends with the act of noticing and cherishing" (Oliver, 99). Harland, pondering her son's autism, starts from this same stance of awareness and affection. Will's autism compels him to crave ritual and predictability, to regulate his sensations to the point where they can be integrated. Instead, he's confronted by the overwhelming confusion of modern life. Harland empathizes with her son, anticipating what will "set him off" into a panic or frenzy. In the process she also manages to convey

how unnatural an environment is the typical city (in this case Seattle), how unforgiving our modern life is of those who think or act or perceive differently from the “norm.”

Like Killilea, both parent-authors go a long way in explaining the particular issues of parents whose children have significant disabilities. Harland and Crane go further, however, in sharing their more intimate struggles and confusion. Harland, for instance, writes with great feeling of the guilt – what we might call the “internalized oppression” – of parents who are encouraged to blame themselves for “what went wrong.” Crane takes it an important step further by putting this urge to blame in a political context. He analyzes, for instance, how parents of kids who need alternate public school services get pitted against the rest of the community, how certain segments of our society begrudge the very existence of people with disabilities.

Killilea, a devout Roman Catholic, like the other authors possess a strong element of spirituality. For Harland, her acute focus on the “here and now” in the service of her son becomes a form of Zen “mindfulness,” while Crane draws heavily from Lao Tzu and the Chinese Taoist tradition. “Disabled people” he concludes, “are not marginal to the human experience, they are central to it,” (Crane, 68-9) and one of the most powerful passages in his book is his refutation of Peter Singer’s “utilitarianism.”

Both Crane and Harland have written for a general audience, but their books would be appropriate texts in any disability studies course at a high school or college level. (For that matter, *Karen* is also still worth reading, despite the occasional lapses into sentimentality). I would urge, however, that they be used as supplements to, and not substitutes for, texts by disabled writers themselves.

References

Oliver, M. (1999). *Winter hours: Prose, prose poems, and poems*. New York: Houghton Mifflin.