

Multimedia

Complexities of Advocacy Alliances: A Book Review of *Allies and Obstacles: Disability Activism and Parents of Children with Disabilities*

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Abstract

Review by Kara Ayers of Allison C. Carey, Pamela Block, and Richard K. Scotch's *Allies and Obstacles: Disability Activism and Parents of Children*. Philadelphia, PA. Temple University Press. 2020.

Keywords: activism, disability, parents, community engagement

Allies and Obstacles: Disability Activism and Parents of Children with Disabilities is an in-depth historical and critical analysis of the documented and largely organized advocacy efforts of parents of children with disabilities. Authors Carey, Block, and Scotch recognize that parent activists have a complicated relationship with disability advocates and that the positions of these two groups often differ. Because parent-led activism is often better funded and brings more power through nondisabled privilege, it has rendered several key victories in the pursuit of lessened stigma and more opportunities for people with disabilities—even more so—for their families.

Still, these victories do not come without a price. As noted by Sauer and Lalvani (2017), a family's quality of life can be negatively impacted by their struggle to access equitable education for a child with a disability. Anecdotal evidence through examples of this impact is shared throughout *Allies and Obstacles*. Societal barriers are cited as the cause of these struggles versus disability itself. Community engagement and grassroots activism may

help reduce the strain of what has often been the sole responsibility of parent advocates and instead invite a shared effort of a larger community.

This book is organized in two sections: Part I compares and contrasts four different specific disability groups and their related parent activism. Intellectual disabilities, psychiatric disabilities, autistic disabilities, and physical disabilities are detailed individually. The authors note an intentional decision to narrow the focus of this macro analysis, which resulted in the exclusion of parent activism for people who are blind, have chronic illnesses, or are members of the Deaf community. There is also the complication of overlap between and among these specific communities.

Part II of *Allies and Obstacles* takes a cross-disability approach. The timing of the emergence of parent-led organizations is considered in context with concurrent social movements. A chapter on “Narrative of Rights” examines the tenuous exchange of privacy, accountability, and self-determination for the rights to access and nondiscrimination. The chapter concludes with a statement that seems more like a question, “Disability rights as imagined by parents may empower people with disabilities or it may empower parents to make decisions for their offspring.”

While the potential conflict of interest between parents and disabled advocates is brought up in a similar manner throughout this contribution to the literature, its importance is never quite emphasized as much as it seems to play out in the advocacy arena. Much of the parent-led advocacy described in *Allies and Obstacles* still stems from a medical and deficits-based model of disability. There seems only periphery interest from parent-led advocacy groups in authentic collaborations with disabled-led groups and even less commitment to intentionally forgoing decision-making power to shift dynamics to be more disability-centered. Vaughan and Super (2019) describe, “a need and responsibility for parents to grapple with alternative understandings of disability.” It does not appear this responsibility will be met soon, but *Allies and Obstacles* stops short of an explicit declaration. This is an unfortunate omission because the book’s conclusion denotes an exploration of points of alliance between parent and disabled activists as a central goal of the book.

This book is recommended for disability scholars interested in a unique appraisal of parent-led advocacy. The framing of strategy related to a rights narrative is of interest to policy advocates. Disability organizational leaders are also advised to read this book to


consider the historical context of parent-led advocacy, power imbalances, and the ongoing volleying of responsibility for greater equity.

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