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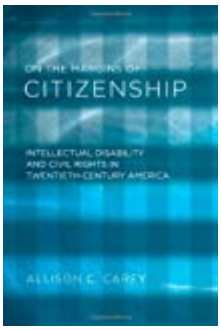


**Allison C. Carey.** *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America.* Philadelphia: Temple University Press, 2009. 286 pp. $59.50 (cloth), ISBN 978-1-59213-697-1.

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## Reconstructing the Ideological History of Disability

*Review Editor's Note: Paul K. Longmore passed away on August 9, 2010.*

Allison C. Careyâs *On the Margins of Citizenship* gives us a valuable ideological history that locates framings of intellectual disability, and thus of people with intellectual disabilities, within the larger context of American ideas about citizenship and rights. Her argument is rich and complex, too complicated to be summarized simply. She shows that in every era ideas about intellectual disability and the experience of people with intellectual disabilities have challenged, conflicted with, or operated in tension with formulations of citizenship and rights. Indeed, people with intellectual disabilities have typically been viewed as deficient for full citizenship, often as the opposite of the ideal citizen, and as not only unworthy of citizenship but also dangerous to the well-being of the community and nation. Yet at the same time, American ideas about intellectual disability have never been permanently fixed. Instead, in each era they have been contested, and they have changed from one era to the next. Despite professional attempts to define intellectual disability with scientific precision, the lived experience of people identified as having those disabilities has varied enormously depending on the historical moments in which they found themselves. Because of those variations, at no time have Americans reached a consensus about the place of people with intellectual disabilities in society and the extent to which they could or should exercise rights. Nondisabled opinion has ranged from demanding their total exclusion to accepting their full equality. The debates not only have involved considerations about the competency, economic productivity, and dependency of individuals labeled intellectually disabled, but have also reflected ideal visions of the national community, the standards for membership in it, and the responses of that community to difference in its midst. For that reason, Careyâs study traces the history of ideologies of intellectual disability as well as the intertwined history of American ideologies constructing rights, the individuals who get to âhaveâ rights, the process of exercising those rights, and the definition of state obligations to non-rights-bearing citizens. In showing how ârightsâ are

not possessions but relational practices, she spells out the practical implications of those understandings for people with intellectual disabilities.

Carey explains that much of the legal history of Americans with intellectual disabilities has been characterized by the formal deprivation of rights. Instead of rights, state legislatures put in place a series of legal âprotections.â For example, men with intellectual disabilities might be exempted from military service, and damaging contracts made by people with intellectual disabilities might be voided. At the same time, they were also commonly barred from voting, sitting on juries, marrying, or attending public schools. âProtectionâ might mean provision of safeguards and services, but also marginalization, segregation, and abuse. Through much of the twentieth century, up until at least the late 1960s, protection by the state often meant compulsory indefinite institutionalization without the consent of the individual. Other âprotectiveâ measures included statutes restricting marriage (thirty-nine states) and requiring sterilization (thirty-four states), the latter raising questions about infringements on the rights of privacy and bodily integrity. In fact, the aim of protective public policies was control of people with intellectual disabilities either within society or by removing them from society. But Carey carefully notes significant exceptions to these policies and practices. For example, some states never adopted marriage restriction or sterilization statutes. This again suggests the absence of full consensus about persons with intellectual disabilities.

Even in the late twentieth and early twenty-first centuries, when people with intellectual disabilities were increasingly granted and supposedly guaranteed their ârights,â the practical realities of their situations often precluded meaningful exercise of those rights. For example, many adults living in community residential facilities had virtually no say about where and with whom they lived or what they did on a daily basis, even if they held jobs. Instead, to receive services they had to surrender these sorts of decisions to professionals who managed them. Segregation in key areas, such as public education, public transportation (in the form of paratransit), and employment (for instance, in sheltered workshops), bolstered their continuing marginalization and disempowerment. De facto deprivation of the rights guaranteed on paper reinforced their general lack of control over their lives.

Carey corrects the historically false view of an early twentieth-century era of relentless oppression giving way to a late twentieth-century period of progressive inclusion. She shows that during the early twentieth century there were always advocates resisting discrimination and asserting the rights of people with intellectual disabilities, while in the late twentieth century and beyond old ideas about incompetence, dependency, and deviance persisted in justification of the deprivation of rights.

Carey makes a useful and important contribution to our understanding of the periodization of disability history. She shows that the mid-twentieth century, the 1940s and 1950s, has received too little attention from historians regarding the history of intellectual disability. These decades marked an important transitional moment in which the seeds of many reform ideas were planted and began to blossom. For example, during the 1940s a few professionals supported the rights of some people with âmental retardationâ to receive rehabilitative services, and during the 1950s parent advocates fashioned a new image of the âspecial child.â Though paternalism persisted, this era was nonetheless foundational in introducing what in later years would become arguments for the civil rights of people with intellectual disabilities. In calling attention to the historical significance of those decades, her work suggests that historians need to consider possible parallels with recent work in other areas of disability history, for example, Audra Jenningsâs study of the American Federation of the Physically Handicapped. The 1940s and 1950s may have been a transitional moment for people with various disabilities, an era of change that set the stage for the greater activism and broader transformations of the late twentieth century.

Carey reconstructs changing narratives of intellectual disability in each era of the twentieth century. Any brief attempt to summarize her explanations inevitably oversimplifies their complexity and richness. In the early decades, people labeled âfeeblemindedâ were depicted as vocationally and socially incompetent, economically unproductive, sexually out of control, and burdensome, even dangerous, a âmenaceâ to society. In the post-World War Two era, parent advocates produced a counter-narrative of the âspecial child,â innocent, selfless, a gift from God, in need of and entitled to lifelong protection, support services, and guidance from the state and society. In the 1960s, advocates presented another narrative of the productive citizen who, with appropriate education, rehabilitation, and support services, could be a responsible and contributing member of society. In the late twentieth century, still another narrative portrayed people with intellectual disabilities as competent

to function as independent, productive, and moral rights-bearing and rights-exercising citizens. My thumbnail descriptions of these successive narratives obscures one of Careyâs major points: in any era, counter-narratives contested these dominant narratives. Further complicating this history, advocates had to negotiate and accommodate their framings to make their cases persuasive within particular historical and ideological contexts. In other words, multiple narratives were to a degree pragmatically fashioned simultaneously within their specific historical moments.

Much of the ideological history of intellectual disability appears in legislation and court rulings. Carey provides concise summaries and critical analyses of a large number of major legislative acts and judicial decisions, ranging from the model eugenics statutes of the early twentieth century to the Developmental Disabilities Assistance and Bill of Rights Act (1975) to the Americans with Disabilities Act (1990), from *Buck v. Bell* (1927) to *City of Cleburne, Texas v. Cleburne Living Center* (1985) to *Atkins v. Virginia* (2002).

Whether analyzing court cases, personal memoirs, advocacy statements, professional research, or other sources, Carey examines concepts of both intellectual disability and rights, the interplay between the two, changing ideologies and strategies across time, and the problematics of every position. She is careful to explain that her analysis of the evolving historical construction of intellectual disability does not exclude an understanding of it having a biological basis. Rather, as with all disability studies, she contests the traditional assumption of an objectively measurable, clinical condition. She persuasively shows that the historical myriad of labels–idiot, imbecile, feebleminded, mentally deficient, backward, incompetent, mentally retarded, mentally handicapped, mentally disabled, developmentally disabled, cognitively disabled, intellectually disabled–all had particular meanings in their historical contexts and, more important, reflect the changing social and cultural meanings of intellectual disability over time.

Throughout the twentieth century, to make the case for rights-bearing citizenship, advocates had to grapple with core concepts in the liberal theory of citizenship, the traits regarded as essential to authentic American personhood and citizenship: rationality, social competency, economic productivity, and self-sufficiency, all defined as the necessary basis of self-determination and autonomy. Advocacy had to counter popular and professional perceptions of people with intellectual disabilities as the opposite of this ideal, namely, mentally deficient, socially incompetent, economically unproductive, and, as a result, psychologically, economically, and socially dependent. In response, late twentieth-century advocates borrowed from feminist critiques of notions of womenâs âdependencyâ to develop disability-based ideas of interdependency and reciprocity. Carey also provides an excellent critical discussion of activistsâ efforts to move beyond the limitations of American civil rights theory to ground claims of social and economic rights within a broader human rights framework. As with so much of her analysis, this section of the book will be particularly useful for scholars doing a comparative historical and ideological analysis of various disability rights movements.

One of the most valuable and historically revealing contributions of this book is its concise overview of the emergence of self-advocacy groups, such as People First and Self-Advocates Becoming Empowered (SABE). As with other ideologies, Carey critically examines the ideology of intellectual disability formulated by activists with intellectual disabilities. She also traces their alliances, and sometimes tense relations, with organizations of professionals, parents groups, and activists in other disability rights movements.

Also impressive is her interweaving of the distinct histories of various advocacy movements on behalf of people with intellectual disabilities. One of the most important was the parents movement that arose just after World War Two. The interactions and conflicts among multiple differing advocacy groups within the larger movement around intellectual disability present another parallel with the histories of other disability movements. We need more comparative historical analyses of the features of those various campaigns. In addition to providing an excellent history of intellectual disability in modern America, Carey has given us a model of the questions we need to ask and the themes we need to trace in the ideological histories of all disabilities. A series of such comparative studies can provide the foundation for a comprehensive historical understanding of âdisability.â Careyâs important book will help lay that foundation.

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