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Defining Disability in California State Law During the Twentieth Century

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By

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Professor Elena Conis
Professor Osagie Obasogie

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Abstract

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This dissertation traces the development and evolution of disability as a legal concept in California during the twentieth century. It begins by analyzing how disability came to be understood through a medical lens assessing an individual's capacity to work from the late eighteenth century, through the nineteenth century, and into the early twentieth century.

The second chapter shows how the California state legal system joined medical professionals in favoring expansion of private care at the expense of government-sponsored alternatives, while at the same time steering private care toward acceptance of group insurance over traditional fee-for-service. It pays particular attention to cases involving Kaiser Permanente's group prepayment program as a model for expansion of private health care coverage that continued to exclude those in desperate need of care—the unemployed, those with disabilities, and those with lower incomes.

The third and fourth chapters turn to activists and state officials in California to illustrate how disability as a legal concept shifted from an emphasis on work, welfare, and rehabilitation to a focus on engagement, inclusion, and assimilation in all aspects of life through the independent living movement. The third chapter analyzes activists' efforts to work with and against state officials to change how they were perceived and what opportunities they could pursue. The story of Cowell, Berkeley, PDSP and the Centers for Independent Living is a story of individuals who strove for individual freedom and then entered the halls of state power to steer those same expansions of freedom.

The fourth and final chapter reveals how activists could implement their reconceptualized definition of disability into state law through bureaucratic channels. Proud activists-turned-bureaucrats were able to work within the system that they had previously rebelled against to codify their vision of inclusion and assimilation in society through state funding that was necessary for independent living centers to operate. Ultimately, this dissertation analyzes the ways advocates inside and outside of state institutions can alter legal definitions and garner state support.

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Acknowledgments

During my time as a graduate student at U.C. Berkeley I have lived in the South Berkeley neighborhood. The routine of a typical day is as follows. My dog Bella wakes me up, eager for a walk. Our normal stroll is down the street half a block, take a right, and then another quick right. On that street, Ward Street, we pass the houses where disability activist Ed Roberts and his mother Zona lived for a time, as well as the house of the Assemblyman who wrote the bill to fund independent living centers, Tom Bates. I then take Bella home, get ready for the day, and leave for another walk, this time alone to U.C. Berkeley School of Law.

I walk down the street to Telegraph Avenue and turn north toward campus. As I pass Blake Street, there is a plaque on the side of the building marking one of the early locations of the Center for Independent Living, the first independent living center. A few hundred more yards up the road I reach Durant Avenue, where there is a plaque on the ground commemorating the first curb ramps installed by the City of Berkeley. My research has informed me that this may be the first official recognition of curb ramps, but activists had been roaming the streets of Berkeley at night laying down asphalt in the dark to create their own accessible environment long before the city began to officially build curb ramps.

I then take a right on Durant Avenue and pass Top Dog, the famous Berkeley food joint, behind which was the first office of the Physically Disabled Students' Program (if you do not include John Hessler's apartment). After doing some work at the law school, I would often head north deeper into campus, passing by the business school with a plaque outside, this one commemorating the location of Cowell Hospital, where students with disabilities first lived at U.C. Berkeley. I would walk home down those same streets, and if I went into San Francisco to visit friends, I would often pass the Ed Roberts Campus housing the Disability Rights Education and Defense Fund, and the Center for Independent Living. On my way down to the Ashby BART station I would see the plaque recognizing the contributions of Hale Zukas, another disability activist who devoted much of his life to making transportation, like BART, accessible to those with disabilities.

This project has not just enriched my life as a student of law and disability, but as a resident of Berkeley and a citizen of California. My first thank you is to these activists, who not only worked to change the laws, environments, and social attitudes surrounding disability, but also lived in these neighborhoods and improved them for generations to come. I also thank them for the papers they left and the oral histories they provided for future research.

Those papers and oral histories are cared for by wonderful archivists who have helped me during my time in Berkeley. Therefore, I also want to thank the archivists at the Bancroft Library at U.C. Berkeley and the archivists at the California State Archives for their help.

The Jurisprudence and Social Policy program has been a great place to work, study, and grow as a young academic. The faculty have been very gracious with their time and attention. I want to thank a few in particular, Professors Catherine "KT" Albiston, Christopher Kutz, Kinch Hoekstra, Dylan Penningroth, and Cal Morrill. This dissertation is not possible without the committee members, and I want to thank Professors Elena Conis and Osagie Obasogie for their guidance during this project.

My fellow students and candidates have also helped me along this journey, and I would like to thank original cohort members for their support, Diana Reddy, Yan Fang, Joel Sati, and

Celina Romano. Thank you also to support from fellow historians in the program, Kyle Deland and Kavitha Iyengar. Two friends have been especially supportive, I want to thank Colin Christensen and Lawrence Liu for their friendship along the way.

I met my advisor and dissertation chair, Professor Christopher Tomlins, before I was a student at Berkeley. I was getting my master's degree and interested in pursuing a law degree and Ph.D. I sent him an email out of the blue asking if he would have time to meet and discuss the Jurisprudence and Social Policy program at U.C. Berkeley School of Law with an unknown graduate student at a completely different institution. He was not only willing to discuss it, but he also offered advice and guidance during a long conversation about both the program and academia generally. It was the first of many instances where Chris would generously provide plenty of time to talk, and eventually edit my work (extensively and thoroughly, for which I am forever grateful). He was not only a major reason I came to Berkeley, but also a major reason I enjoyed it so much and I learned as much as I have. I owe a great deal to him for his advice and guidance during my time here—thank you.

I would like to thank Allyson Bakos, for her encouragement and support in these last few months. Special thanks also goes to my brother and sister, Keith and Heather Sangster, and my soon-to-be brother in law William Becker, who have all been incredible in their support and providing such fun study breaks when we visit each other. Dogs really are our best friends, and Bella is no exception. It has been wonderful taking her for walks around sunny Berkeley.

Finally, the biggest thank you is reserved for my parents. This education and life experience would not have been possible without them. I really cannot find the words to express the gratitude necessary to reflect their efforts and contributions. All I can do is say thank you. This dissertation is dedicated to them, Carol and Graham Sangster.

Introduction

Lynn Thompson wanted to work and live independently. Living in the Sepulveda neighborhood of Los Angeles, California during the 1970s, Thompson experienced muscular dystrophy; the agony was so excruciating that she had her legs disconnected from her hips to alleviate some of the pain. She was classified by the Social Security Administration (SSA) as "totally disabled" and incapable of engaging in "substantial gainful activity." She received welfare benefits that included Medi-Cal, attendant care, and Supplemental Security Income. After paying $285 for rent she had very little spending money, and so she started working as a telephone dispatcher where she earned $492 per month. In 1976, an individual could not earn more than $230 per month and still receive benefits. She did not hide her employment, on the contrary, it was publicized in local newspapers; but she also did not report it to the SSA. Years passed and when the SSA finally did find out, it rescinded her benefits and mandated that Thompson pay back the money for those benefits, amounting to approximately $10,000. Facing a crippling debt and a loss of independence, Thompson felt trapped. In February of 1977, seeing no way out, she killed herself.[1] In her recorded message before her suicide, Thompson explicitly blamed the SSA for her final fatal decision:

> "Give Social Security a message for me. Tell them thanks for being the straw that broke the camel's back…It would be great if I could work and support myself and still receive the full attendant's benefits and some kind of medical benefits…If I ever get to the point where I can make $1,200 or $1,500 a month, fine. They can keep their money and the medical insurance. I wouldn't need them then. But for $492 of salary it's just not enough to pay these expenses."[2]

The plight of Lynn Thompson illustrates multiple issues that stem from the legal construction of the "disabled" category in American law during the twentieth century. First, it illustrates the centrality of a medical assessment when establishing a disability under the law. Disability can be understood through two lenses, the internal view of the individual experiencing the condition, and the external view of medical assessments and examinations by medical professionals and administrators.[3] Activists have argued that the internal view should be prioritized over any external view, claiming that those experiencing a physical or medical condition are best equipped to assess it and prescribe solutions to mitigate the conditions, such as benefits or accommodations.[4] However, throughout American history and within contemporary

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[1] Douglas A. Martin, *National Leader in Reforming Social Security and Medicare Disability Programs; ADA/504 Compliance Officer at UCLA; First Executive Director of the Westside Center for Independent Living,* an oral history conducted by Lou Breslin in 2002 in *Shaping National Disability Policy: Transportation Access and Social Security Reforms*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2004, 124-125; "Coalition urges moratorium," Paraplegia News, April 1978, 27; Terry Brickley, "Handicapsules," Column, Santa Cruz Sentinel, May 22, 1978, 4; Terry Brickley, "Handicapsules," Column, Santa Cruz Sentinel, May 30, 1978, 13; Sonny Kleinfeld, "Declaring Independence in Berkeley," *Psychology Today*, August 1979, in the Deborah Kaplan Papers at the Bancroft Library, University of California, Berkeley, BANC MSS 99/369, Carton 1; Social Security, Substantial Gainful Activity, https://www.ssa.gov/oact/cola/sga.html.

[2] Terry Brickley, "Handicapsules," Column, *Santa Cruz Sentinel*, May 30, 1978, 13.

[3] I take this internal/external distinction from Amartya Sen, *The Idea of Justice* (Cambridge, Mass.: Harvard University Press, 2009), 284-285.

[4] Douglas Martin, oral history, Bancroft Library, 119; Judith Heumann, "Pioneering Disability Rights Advocate and Leader in Disabled in Action, New York: Center for Independent Living, Berkeley; World Institute on Disability;

legal understandings of disability, medical evaluations are often essential to establish a legal disability and dispositive in judicial opinions and administrative decisions determining disability.[5] How Lynn Thompson experienced muscular dystrophy and what she felt she could do with it (the internal view), as opposed to how others in medical and administrative apparatuses viewed what she could do (the external view), is a tension present in many cases for those considered disabled. Thompson's plight reveals the stark and at times devastating relationship between ability and work when defining "disability" as a legal category. Here, what determined whether Thompson was disabled was her earning capacity—by earning more than $230 she was deemed no longer disabled before the law. Nothing about her physical ability had changed; she still suffered from muscular dystrophy and required attendant care. However, her income came to define her as no longer disabled and hence no longer eligible to receive the benefits necessary to live and work as she had been doing. This distinction can be understood in the wake of social, economic, and medicinal forces that established disability as a legal category in the eighteenth and nineteenth centuries. Medical evaluations of an individual's capacity to work in large industrial economies came to define disability in the first half of the twentieth century. This is the subject of the first chapter of this dissertation.

Second, Thompson's experience demonstrates the importance of clear promulgation and comprehension of laws and regulations related to disability benefits and accommodations. State entities need to make recipients aware of the benefits, and recipients need to be able to understand the nature and degree of those benefits. Her case shows how the federal divide can lead to misconceptions and gaps of coverage. As we will see in chapter two, is no single American public health care system, there are many separate health care systems at the federal, state, and county levels, and within this patchwork there are different departments and agencies that address different health needs.[6] Thompson's experience at the hands of the federal and state systems drove her to what a reader of the Santa Cruz Sentinel called "bureaucratic homicide."[7]

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and the US Department of Education 1960s-2000," an oral history conducted by Susan Brown, David Landes, Jonathan Young in 1998-2001, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2004, 60-61; Ed Roberts, Oral History in *University of California's Cowell Hospital Residence Program for Physically Disabled Students, 1962-1975: Catalyst for Berkeley's Independent Living Movement*, Regional History Office, The Bancroft Library, 26-27, Michael Oliver, *Understanding Disability: From Theory to Practice, Second Edition*, (New York: Palgrave Macmillan, 2009), 35, 171-172; Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Three Rivers Press, 1994), 51; E.K. Schneider and J.J. Simeone, "Pain and disability under Social Security: time for a new standard," Journal of Health Law, 2001 Summer; 34(3):459-85 (discussing how those experiencing fibromyalgia cannot always be medically assessed as such and subjective testimony should suffice in establishing disability).

[5] Oliver, *Understanding Disability*, 64-65; Deborah Stone, *The Disabled State* (Philadelphia: Temple University Press, 1984), 68-89; Craig Konnoth, "Medicalization and the New Civil Rights," 72 *Stanford Law Review* 1165 (2020), 1172, 1175-1184; Deirdre M. Smith, "Who Says You're Disabled? The Role of Medical Evidence in the ADA Definition of Disability," 82 *Tulane Law Review*, 1 (2007), 4-5; Frank S. Bloch, "Medical Proof, Social Policy, and Social Security's Medically Centered Definition of Disability," 92 *Cornell Law Review* 189 (2007); Keith Wailoo, *Pain: A Political History* (Baltimore: Johns Hopkins University Press, 2014), 45.

[6] Laura D. Hermer, "Federal/State Tensions in Fulfilling Medicaid's Purpose," 21 Annals Health Law, 615 (2012), 618-619; Nicole Huberfeld, "Post-Reform Medicaid before the Court: Discordant Advocacy Reflects Conflicting Attitudes," 21 Annals Health Law, 513 (2012); Jane McCahill & Joseph T. Van Leer, "The Challenges of Reform for Medicaid Managed Care," 21 Annals HEALTH L. 541 (2012), 548; Jamila Michener, *Fragmented Democracy: Medicaid, Federalism, and Unequal Politics*, (Cambridge: Cambridge University Press, 2018), 8, 13; Sara Rosenbaum, "Medicaid at Forty: Revisiting Structure and Meaning in a Post-Deficit Reduction Act Era," Journal of Health Care Law & Policy 9 (2006) 5, 8-16;, Robert Stevens and Rosemary Stevens, *Welfare Medicine in America: A Case Study of Medicaid* (New York: The Free Press, 1974), 28-29, 32, 58-59; Shapiro, *No Pity*, 261, 265-269.

[7] Terry Brickley, "Handicapsules," Column, Santa Cruz Sentinel, May 22, 1978, 4.

Tragically, California had passed a law that had allowed for incremental adjustments to benefits as an individual increased their employment and salary.[8] If Thompson had known that the state had passed this law, she would have been able to take advantage of it and adjust her benefits incrementally based on her income.

Third, Thompson's case emphasizes the connection between an individual's abilities and the environment around them—what is called the distinction between the medical model and social model of disability. Many scholars have slightly different definitions of each model, but the main point is that the medical model seeks to change the person, while the social model seeks to change the environment.[9] In chapters three and four, I will explore the extent to which the shift from the medical model to the social model is manifested historically by analyzing the performance of important actors in this shift, such as activists, state officials, state institutions, and private health care providers in California during the period from 1954 to 1980.

A clear conflict of these two models occurred in Berkeley and throughout California during the 1960s and 1970s. California was a hotbed for disability activism and legal change during this time. Many activists who were educated and who protested in the state became important actors within the legal apparatus against which they were protesting. This emphasis on activists in California provides insight for several reasons. First, it allows me to show how activists outside the legal apparatus were able to develop an awareness of group identity across different conditions that have been classified as disabled, and to form a movement pushing for autonomy and independence. From those with visual impairments to those with walking impairments, individuals considered disabled organized and advocated to alter the legal categories of disability. Second, I am able to analyze how these activists entered the legal system that they fought against to make change from within the state apparatus at both the state and federal levels. Ed Roberts, Judith Heumann, James Donald, John Hessler, Tom Bates and others advocated for change outside the legal apparatus and then went on to work within that very same system to make change from the inside. When activists accused Ed Roberts of selling out by taking the position of Director of the California Department of Rehabilitation, he said, "I'm not a bureaucrat, I'm an advocrat!"[10] These narratives of activists-turned-bureaucrats offer insight into how those who argued outside the legal system for change were able to implement that change as insiders within the legal system.

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[8] Martin, Oral History, Bancroft Library, 124-125; Kleinfeld, "Declaring Independence," 68.

[9] Samuel R. Bagenstos, *Law & the Contradictions of the Disability Rights Movement* (New Haven: Yale University Press, 2009), 18-20; Samuel R. Bagenstos, *Disability Rights Law: Cases and Materials, Second Edition* (St. Paul: Foundation Press, 2014), 4 Edward D. Berkowitz, *Disabled Policy: America's Programs for the Handicapped* (New York: Cambridge University Press, 1987), 8-9; Eric Garcia, *We're Not Broken: Changing the Autism Conversation* (New York: Harvest, 2022) 44, 111; Paul K. Longmore and Lauri Umansky, "Introduction," in Longmore, Paul K. and Lauri Umanski, eds, *The New Disability: American Perspectives* (New York: New York University Press, 2001), 12; Ruth O'Brien, "From a Doctor's to a Judge's Gaze: Epistemic Communities and the History of Disability Rights Policy in the Workplace," 35 *Polity*, 329, 337; Michael Oliver, *Understanding Disability: From Theory to Practice, Second Edition* (New York: Palgrave Macmillan, 2009), 42-43; Larry M. Logue and Peter Blanck, *Race, Ethnicity, and Disability: Veterans and Benefits in Post-Civil War America* (New York: Cambridge University Press, 2010), 1-2; Harlan Hahn, "The Politics of Physical Differences: Disability and Discrimination," *Journal of Social Issues* 44 (1988), 39-40; Sharon Barnartt, Kay Schriner, and Richard Scotch, "Advocacy and Political Action," in in *Handbook of Disability Studies* eds. Gary L. Albrecht, Katherine D. Seelman, and Michael Bury (Thousand Oaks: Sage Publications, 2001), 430-431; Eric Garcia, *We're Not Broken: Changing the Autism Conversation* (HarperCollins: New York, 2021), 44; Liz Moore, "I'm Tired of Chasing a Cure," in *Disability Visibility: First-Person Stories from the Twenty-First Century* ed. Alice Wong (New York: Penguin Random House, 2020), 75.

[10] Douglas A. Martin, oral history, Bancroft Library, 161.

Through this project, I have explored the resources and accommodations that were available to people like Lynn Thompson—and as important, not available—at the federal, state, and county level. Both the availability of these resources to Thompson, and her access to them, were contingent on her being legally classified as "disabled." Starting in the 1930s, the United States underwent major legal transformations in providing health care through the passage of the Social Security Act in 1935. The period after World War II was considered the heyday for rehabilitation and the medical model of disability; medical professionals focused on changing the individual to fit a specific work environment.[11] Then in 1954, the federal government enacted the first law that applied widely to disabled American citizens through an amendment to the Social Security Act. Unlike previous federal laws related to disability, the amendment was not limited to a specific class of people, such as veterans, children, or the blind. However, it was still closely tied to work, as it was dependent on payments into the Social Security fund and qualified as a "disability freeze" that allowed applicants for Social Security to remove a period of disability from the income used to calculate old age and survivors insurance.[12] Two years later, in 1956, the Social Security Act would be amended to provide disability benefits directly to recipients.[13] In 1973 and 1974 the Rehabilitation Act would tie federal funding to accessibility for those with disabilities.[14] The ADA (1990) was meant to symbolize a shift to the social model that emphasized changing the environment to accommodate all individuals.[15]

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[11] David Pettinicchio, *Politics of Empowerment: Disability Rights and the Cycle of American Policy Reform* (Stanford: Stanford University Press, 2019), 31, 35-37; Ruth O'Brien, *Crippled Justice: The History of Modern Disability in the Workplace*, (Chicago: University of Chicago Press, 2001), 40-52; Kenneth W. Hamilton, *Counseling the Handicapped in the Rehabilitation Process*, (New York: The Ronald Press Company, 1950), *passim*.

[12] 42 USCA §416(i); *Bostick v. Folsom*, 157 F. Supp. 108, 111-12 (W.D. Ark. 1957); *Teeter v. Flemming*, 270 F.2d 871, 872 (7th Cir. 1959). For example, if someone was making $X income, but after a disability they received $X/2, the calculation used to determine benefits would remove the period in which they were receiving half their salary ($X/2).

[13] 42 USCA §423; Jill Quadagno, *One Nation, Uninsured: Why the U.S. Has No National Health Insurance*, (New York: Oxford University Press, 2005), 54-55; Jacqueline Vaughn Switzer, *Disabled Rights: American Disability Policy and the Fight for Equality*, (Washington D.C.: Georgetown University Press, 2003), 52; Berkowitz, *Disabled Policy*, 41; Dominick Pratico, *Eisenhower and Social Security: The Origins of the Disability Program*, (Lincoln: Writers Club Press, 2001), 37-49; Daniel Béland, *Social Security: History and Politics from the New Deal to the Privatization Debate*, (Lawrence: University Press of Kansas, 2005), 126-127; Deborah A. Stone, *The Disabled State*, (Philadelphia: Temple University Press, 1979), 76-78; David Pettinicchio, *Politics of Empowerment: Disability Rights and the Cycle of American Policy Reform*, (Stanford: Stanford University Press, 2019), 43; Keith Wailoo, *Pain: A Political History* (Baltimore: Johns Hopkins University Press, 2014), 3-4, 17.

[14] Edward D. Berkowitz, *Disabled Policy: America's Programs for the Handicapped* (New York: Cambridge University Press, 1987), 212-215; Robert L. Burgdorf Jr., Substantially Limited Protection from Disability Discrimination: The Special Treatment Model and Misconstructions of the Definition of Disability, 42 Villanova Law Review 409 (1997), 414-417; Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2012), 165-167; Ruth O'Brien, "From a Doctor's to a Judge's Gaze: Epistemic Communities and the History of Disability Rights Policy in the Workplace," 35 *Polity*, 328-329; Richard K. Scotch, *From Good Will to Civil Rights: Transforming Federal Disability Policy*, (Philadelphia: Temple University Press, 2001), *passim*.

[15] Samuel Bagenstos, "The Future of Disability Law," 114 Yale L. J. 1 (2004), 19; Claudia Center and Andrew J. Imparato, "Redefining Disability Discrimination: A Proposal to Restore Civil Rights Protections for All Workers," 14 Stan. L. & Pol'y Rev. 321 (2003), 331; Elizabeth F. Emens, "Disabling Attitudes: U.S. Disability Law and the ADA Amendments Act," *American Journal of Comparative Law* 60 No. 1 (Winter 2012), 214; Katharina Heyer, "Law and Disability," in *The Handbook of Law and Society*, eds. Austin Sarat and Patricia Ewick (John Wiley and Sons, 2015), 323-328; David Pettinicchio, *Politics of Empowerment: Disability Rights and the Cycle of American Policy Reform*, (Stanford: Stanford University Press, 2019), 2, 50-51; Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement*, New York: Three Rivers Press, 1994), 8-9, 323-324; Richard K.

Despite the gains of the Disability Rights Movement in the twentieth century, there are still legal provisions defining disability through a medical lens. Regarding disability benefits, the Social Security Act still defines "disability" as "medically determinable" under provisions for both Old Age, Survivors, and Disability Insurance (OASDI) and Supplemental Security Income (SSI).[16] The second prong of the definition under the ADA states that "a record of impairment" can be used to establish a disability.[17] While the definition has expanded under the ADA, this second prong shows that a medical record can still be dispositive in establishing a disability under the law.

The first chapter of my dissertation traces how the legal conception of "disability" developed from the eighteenth century into the twentieth century through an analysis of literature related to disability, law, and health care in the United States. The analysis of the nineteenth century will focus on three developments that would influence the legal conception of disability in the twentieth century. First, the increase of population led to anonymity of individuals within communities. Second, the emergence of industrialist economic production valued a uniform and replaceable labor force. Third, an intensified medical professionalism and specialization would assess individuals through technical medical analysis. All three of these developments in the nineteenth century worked to conceptualize disability based on medical assessments of anonymous individuals' capacity to work. I then show how the workmen's compensation laws and programs for wounded veterans emphasized the importance of vocational rehabilitation in aiding those considered disabled, rather than government benefits.

This formulation created in the decades before the Social Security Act would be used to determine access to benefits and accommodations related to disability in the twentieth century. Federal and state provisions related to creating disability as a legal category defined disability through the lens of work and medical assessment. An example of this in particular is the passage of the amendments to the Social Security Act that defined disability and were interpreted by courts and administrators through judicial decisions and administrative rulings. Under the Social Security Act, as amended, "disability" was defined as an "…inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or to be of long-continued and indefinite duration…"[18] Social Security rulings and appeals to the federal judiciary demonstrate how medical testimony and reports from a physician were often dispositive in establishing disability.[19] These cases reveal not only how disability was defined, but also how the law

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Scotch, *From Good Will to Civil Rights: Transforming Federal Disability Policy*, (Philadelphia: Temple University Press, 2001), 6-7, 34.

[16] Frank S. Bloch and Jon C. Dubin, *Social Security Law, Policy, and Practice: Cases and Materials* (St. Paul: West Academic Publishing, 2016), 179-180; 42 U.S.C. § 423(d)(1)(A); 42 U.S.C. § 1382c(a)(3)(A).

[17] Bagenstos, *Disability Rights Law*, 10; 42 U.S.C. § 12102(1)(B).

[18] 42 U.S.C.A. §416(i)(1), 42 U.S.C.A. §423(c)(2).

[19] For examples of Social Security Rulings determining disability eligibility based on medical evidence following the amendments, see: SSR No. 61-68 (1961) claimant's impairment established through medical evidence, but the ability to use second arm means he can engage in substantial gainful activity; SSR No. 61-63 (C.E. 1961), physician provided medical evidence of physical and cerebral impairment, establishing a state of disability; SSR No. 61-10 (C.E. 1961), medical evidence used to establish impairment of paralysis on right side of body; SSR No. 61-69 (C.E. 1961), medical evidence corroborated incapacitating degenerative cerebrospinal disease; SSR No. 62-71 (C.E. 1962), medical reports found "mild" symptoms and conditions that led to decision of no disability, as the impairment was not severe enough; SSR No. 63-14 (C.E. 1963), medical reports from physicians hired by the claimant and hired by the government both suggested that claimant could not engage in physical labor; SSR No. 63-25c (C.E. 1963), conflicting physicians' testimonies and medical reports provided examiner with sufficient

excluded some from access to disability benefits. They show where the law was, and where it was not. The law was in the physician's office, and those who did not have access to physicians did not have access to the law. In this first chapter I will try to answer questions such as: How

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"substantial evidence" to deny benefits; SSR No. 64-29c (C.E. 1964), conflicting medical evidence is an issue of fact, sufficient evidence to deny claim; SSR No. 64-11c (C.E. 1964), despite two physicians finding that claimant was precluded from performing work, a third doctor with more tests found that claimant was not totally disabled, *despite the third doctor being outnumbered, medical evidence of tests was sufficient and dispositive*; SSR No. 64-46c (C.E. 1964), after remand from appellate court, further evidence suggests claimant could engage in substantial gainful activity; SSR No. 64-32 (C.E. 1964), medical discharge from Air Force, and exacerbation of symptoms since, provide evidence for condition of disability; SSR No. 64-28c (C.E. 1964), conflicting medical evidence allows for finder of fact to make decision against claimant; SSR No. 65-15c (C.E. 1965), medical evidence outweighs subjective testimony of claimant, enough conflicting medical evidence allows for denial of benefits; SSR No. 65-61c (C.E. 1965), stresses that it is incumbent upon the plaintiff to demonstrate disability through medical evidence, and failed to do so here; SSR No. 65-47c (C.E. 1965), after remand for further evidence, claimant went to a heart specialist that found impairment to be less severe than previous evidence suggested; SSR No. 65-58c (C.E. 1965), medical evidence did not corroborate plaintiff's subjective complaint, multiple doctors disagreed over extent of injury, enough evidence on both sides for denial to stand; SSR No. 65-12c (C.E. 1965), medical evidence and placement on military disability retired list sufficient to establish disability.

For examples of federal judicial decisions assessing medical evidence in appeals of administrative decisions regarding disability eligibility, see: *Fuller v. Folsom*, 155 F. Supp. 348 (W.D. Ark. 1957), subjective opinion of the plaintiff needs to be substantiated by medical evidence to establish a disability; *Ussi v. Folsom*, 157 F. Supp. 679 (N.D.N.Y. 1957), permanent partial disability does not meet requisite standard for disability; *Bostick v. Folsom*, 157 F. Supp. 108 (W.D. Ark. 1957), medical evidence provided by physicians outweighs medical evidence provided by consultants; *Jacobson v. Folsom*, 158 F. Supp. 281 (S.D.N.Y. 1957), case remanded so that the plaintiff can introduce further medical evidence; *Dunn v. Folsom*, 166 F. Supp. 44 (W.D. Ark. 1958), court rules physicians contrasting opinions outweigh the referee's ruling, substantial evidence of disability established by their medical reports; *Hill v. Fleming*, 169 F. Supp. 240 (W.D. Pa. 1958), physicians' opinions of total disability dispositive in overruling administrative decisions; *Aaron v. Fleming*, 168 F. Supp. 291 (M.D. Ala. 1958), referee's decision imposes drastic standard of claimant needing to be bedridden, too high a standard, no medical evidence countering plaintiff's claim; *Lewis v. Flemming*, 176 F. Supp. 872 (E.D. Ark. 1959), multiple physicians assess plaintiff as having severe arthritis, should not lift more than a plate of food, plaintiff's subjective assessment corroborated by physicians; Klimaszewski v. Flemming, 176 F. Supp. 927, (E.D.P.A. 1959), extensive discussion of what type of work the physician believes plaintiff would be able to do; *Kohrs v. Flemming*, 272 F.2d 731 (8th Cir. 1959), physician as expert witness claims plaintiff is totally disabled, and the lack of contradicting evidence makes administrative denial of benefits suspect; *Teeter v. Flemming*, 270 F.2d 871 (7th Cir. 1959), uncontradicted physician recommendation that plaintiff is not able to engage in substantial gainful activity means that recommendation is dispositive; *Adams v. Flemming*, 276 F.2d 901 (2d Cir. 1960), absence of any doctor testimonial or report that plaintiff aligns with administrative rejection of claim for benefits; *Kerner v. Flemming*, 283 F.2d 916 (2d Cir. 1960), physicians established that an impairment existed, but did not speak to whether it allowed plaintiff to engage in substantial gainful activity, more evidence needed; *Ribicoff v. Hughes*, 295 F.2d 833 (8th Cir. 1961), medical reports establish disability, potential remediation through surgery not dispositive, the disability and the plaintiff's life experience do not align with referee's denial of benefits; *Hall v. Flemming*, 289 F.2d 290 (6th Cir. 1961), remanded for further medical evidence of what the plaintiff can do and available employment opportunities; *King v. Flemming*, 289 F.2d 808 (6th Cir. 1961) references *Hall v. Flemming*, need more evidence of what the plaintiff can do and available employment opportunities; *Graham v. Ribicoff*, 295 F.2d 391, 394-395 (9 Cir., 1961), medical reports suggest plaintiff can do some sedentary work, affirms denial of claim; *Roberson v. Ribicoff*, 299 F.2d 761 (6 Cir., 1962), roughly ten medical reports from four doctors used in setting aside decision of the district court and administrative officials, two doctors said that plaintiff probably could not and definitely could not work; *Pollak v. Ribicoff*, 300 F.2d 674 (2 Cir., 1962), medical evidence used to demonstrate debilitating arthritis; *Hodgson v. Celebrezze*, 312 F.2d 260, (3d Cir. 1963), lower court wrong to uphold administrative decision, medical findings and description by plaintiff's physician suggest that the arthritis in the leg was sufficient to establish disability; *Stancavage v. Celebrezze*, 323 F.2d 373 (3d Cir. 1963), medical reports establish physical impairment, and administrative agency did not show that there was employment in the area available for plaintiff.

did the federal legal definition of disability develop in the 1950s with respect to welfare benefits? How was this federal legal definition of disability interpreted by the courts? Did this definition influence state definitions of disability? If so, how? How did the term "substantial gainful activity" become implemented? How did medical understandings of disability become fused with this legal definition? What was the evidence used to establish disability? The answers to these questions are integral to understanding how disability activists in California understood which resources and services were available—and just as importantly, unavailable—to them in the 1950s and 1960s.

My analysis of the early twentieth century also explores how the public-private divide in American health care coverage led to those with disabilities being excluded from private health care coverage. This happened at the federal level, as I show at the end of chapter one, and at the California state level, which I show in chapter two. It reveals that private providers and insurers covered paying, healthy, young individuals, while the state was left caring for the elderly and those unable to work, who often could not pay and needed more services.

The second chapter explores the evolution of California health law and the impact of legal institutions in limiting and categorizing health care coverage. It shows how, beginning in the 1930s, the state's professional medical society went to considerable lengths to fight efforts to expand health care coverage and decrease costs of medical care. In particular, it tracks medical society litigation based on both statutes and constitutional provisions intended to prevent competition from both the state and from group prepayment plans. The chapter shows how the California state legal system joined medical professionals in favoring expansion of private care at the expense of government-sponsored alternatives, while at the same time steering private care toward acceptance of group insurance over traditional fee-for-service. It pays particular attention to cases involving Kaiser Permanente's group prepayment program as a model for expansion of private health care coverage that continued to exclude those in desperate need of care—the unemployed, those with disabilities, and those with lower incomes. Overall, this chapter argues that the legal profession and private medical providers worked together to limit the health care options for Californians with lower incomes and disabilities. It shows how professional medical associations and private providers used state legislation and judicial decisions to create a two-tiered health care system in California that forced those with disabilities and few resources into limited public care, while those considered able-bodied and with sufficient means to pay for medical services were funneled into private care.

The third chapter focuses on early attempts by activists to force change through protest and advocacy. In the 1950s and 1960s those considered disabled developed group consciousness about their conditions and the environmental obstacles preventing their employment and social engagement. The California public university system was often an important forum for those considered disabled to meet and exchange ideas based on different experiences with disability. Universities in both the UC and CSU systems provided empowering educations and cultural exchange to foster a civil rights framework and spark political activism for change.[20] Ed Roberts,

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[20] Brenda Premo, "Founding Director, Dayle McIntosh Center in Orange County; Member, National Council on Disability; Director, California Department of Rehabilitation" an oral history conducted by Kathy Cowan in 2001, in *Rehabilitation, Higher Education, and Independent Living Services in California*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2004, 89, 93, 96-97, 99-100; Ed Roberts, Oral History, 4-5, 29; Dennis Cannon, *Advocate for Accessible Public Transportation in California and Washington, D.C.*, an oral history conducted by Fred Pelka in 2001 in *Shaping National Disability Policy: Transportation Access and Social Security Reforms*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2004, 22-23; Douglas Martin, Oral History, 89-92.

Judith Heumann, and their roles in the Independent Living Movement and §504 sit-in protests have been covered in disability scholarship, but not to the extent that they implemented independent living as a concept in California state law.[21] While they were major players in expanding rights of those considered disabled, there are many other figures who played crucial roles who have not been adequately studied. Drawing on dozens of existing oral histories and an array of archival papers, I dedicate two chapters to studying how these historical figures worked outside and inside the state and federal legal apparatuses to change the legal definition of disability.

The fourth chapter is devoted to how activists entered the federal and state legal apparatuses to change the legal definition of disability and the parameters of the category of disability. I look specifically at the passage of AB 204, which codified independent living in California state law. It was the first time the state legislature provided funding for independent living centers. It was passed while Ed Roberts, John Hessler, and Jim Donald (all Berkeley alumni and former Cowell Hospital residents) worked within the structure of the California Department of Rehabilitation (CADR) to pass the statute. From the outside, activists at independent living centers throughout the state of California wrote to legislators, visited them in Sacramento, and pushed for its passage. Chapter four shows how advocates-turned-bureaucrats worked together to alter the conception of disability and to change how those with disabilities were treated before the law.

This history is meant to reveal much about the disability rights movement, but it is also meant to complicate this history. It is not my intent to label some actors as “protagonists”” nor antagonists.” This history reveals the ways in which seemingly competing forces were often not competitors, and how the enemy was often the ally. In chapter two, Sydney Garfield and Henry Kaiser expanded health care options and implemented pre-payment group plans to provide more affordable care to thousands of workers. They also contributed to the exclusion of unemployed workers who were potentially incapable of work from obtaining access to that health care. California state officials limited the options of individuals with disabilities in the 1950s and 1960s. Ed Roberts was famously told he could not work and was not a worthwhile investment for CADR. High school officials told him he should not expect a cheap diploma. And yet state officials in the form of community college professors and counselors, U.C. Berkeley doctors and administrators, and state legislators provided vital help in creating opportunities, providing resources, and passing crucial legislation. CADR counselors could be restrictive of resources and demanding of clients. Yet Roberts would eventually be its director, and John Hessler and Jim Donald would work with him to provide opportunities to the severely disabled. The intricate weaving of different motives, actions, protests, policy change, and legislation blur the story of noble activists overcoming a corrupt and malicious state entity. There were some myopic and callous state officials. But there were also many who went to great lengths to implement change. Both Roberts and Hessler found out that responding to activists and community needs was not simple when they were in positions of state authority. This dissertation is meant to offer insight into the more complicated relationship between state, private, and activist forces.

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[21] Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Three Rivers Press, 1994), 41; Doris Zames Fleischer and Frieda Zames, *The Disability Rights Movement: From Charity to Confrontation, Updated Edition* (Philadelphia: Temple University Press, 2011), 37-43; Jacqueline Vaughn Switzer, *Disabled Rights: American Disability Policy and the Fight for Equality*, (Washington D.C.: Georgetown University Press, 2003), 74-76; Bagenstos, *Contradictions*, 15-17.

Chapter 1: Tracing the Development of Disability as a Legal Concept, 1750-1950

The history of disability in the United States begins before the founding at the end of the eighteenth century. Three shifts in the United States during the nineteenth century contributed to the conceptualization of disability as the capacity for employment and independence: as the population increased individuals became anonymous in urban centers rather than smaller rural communities; industrialization demanded an American labor force based on uniformity and replaceable workers, rather than the differentiations of an artisan economy; and an increasingly professionalized and specialized class of physicians used medical analysis to assess and address social and economic problems.

In this first chapter, I review the development of disability in the United States since the eighteenth century. The chapter is organized into two parts. The first part (Section I) analyzes how the concept of disability was tied to ideas about work and independence developed during the nineteenth century. The second part (Section II) analyzes how that conception of disability was implemented and perpetuated in American health care institutions in the early twentieth century, with an emphasis on how care for those with disabilities was steered into the public sector rather than private sector.

This chapter lays an important foundation for two major parts of my analysis of California state law and its relationship disabled individuals. First, it shows the macro level at which health care was split into public and private trajectories, with the more lucrative younger insurance clients reserved the private sector, and the older, less lucrative population that would more regularly need medical services steered toward the public sector. Second, it reveals the extent to which disability was tied to employment and independence, through medical evaluations by physicians on patients who barely knew each other, with the goal of assessing the patients' capacity to work. This close medical assessment of capacity to work was how California state government entities like the Department of Rehabilitation would understand what it meant to be disabled when disability rights activists challenged this conception in the 1960s and 1970s.

I: The Groundwork for the Legalization of Disability in the Nineteenth Century

Three major shifts occurred during the nineteenth century that defined disability as an individual's capacity to work and be independent: a growing population meant the creation of concentrations of increasingly anonymous residents in social communities; industrial capitalism promoted a uniform worker to produce in an increasingly mechanized work environment; and new medical knowledge and professionalization meant the creation of a medical profession that sought to view solutions to socioeconomic problems through a medicalized lens.

A. Population Growth and Social Anonymity

As the population of the United States grew in the late eighteenth and early nineteenth centuries, those considered disabled and dependent were no longer cared for by relatives and neighbors, but instead institutionalized and confined. The small communities of the eighteenth century became large urban sprawls in the second half of the nineteenth century, where neighbors and community members became anonymous. With the rise of industrial capitalism, labor requirements became more uniform, and employers sought workers who could be easily plugged into certain roles and replaced based on a "typical" or "normal" worker with uniform mental and physical capacities. The emergence of germ theory and rigid medical understandings of people within certain environments also led to a socio-medical conception of "disability." These three shifts in anonymization, uniformization, and medicalization all contributed to the establishment of disability as a category and defined it relative to work and independence. This category of a disabled person would become codified in American law during the twentieth century in statutes allocating disability benefits and prohibiting discrimination on the basis of disability.

The first major shift in the American history of disability was the increase in social anonymity as a growing population began to change small communities into larger, more anonymous towns and coastal cities in the first half of the nineteenth century. In the second half of the eighteenth century villages and towns cared for those with disabilities through informal measures. Smaller towns and villages meant a social familiarity, where people were often related in some capacity, meaning that if there was someone who experienced blindness, deafness, or a physical impairment, then the community of relatives and friends would assist and accommodate them. Those with impairments were integrated within the community rather than expelled to institutions. If someone needed food or housing, their family and neighbors were able to support them in their own homes and with their own supplies.[22]

Despite the integration of those with disabilities in the colonial period, the physical and social environment still influenced perceptions of disability, especially within the context of slavery. Africans who were considered disabled were considered "useless" and killed if they could not be used for slavery; for example, those determined to be blind were thrown overboard and drowned during the transatlantic crossing.[23]

Removing those considered disabled from the communities would not occur on a large scale until the nineteenth century. Asylums did slowly begin to emerge in coastal cities as the population grew and anonymous individuals moved into and out of communities. Anonymity proliferated to the point that a new response to dependency was established – institutionalization in the form of the asylum. [24]

In the early republic many communities considered the legal system's treatment of individuals, God's wrath, and the individuals themselves to be the sources of disability, but this

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[22] Nielsen, *A Disability History of the United States*, 20-27; David J. Rothman, *The Discovery of the Asylum: Social Order and Disorder in the New Republic* (New Brunswick: AldineTransaction, 2008), 12, 19-23; Lawrence M. Friedman, *A History of American Law: Third Edition* (New York: Touchstone, 2005), 150-151; Sarah F. Rose, *No Right to Be Idle: The Invention of Disability, 1840s-1930s*, (Chapel Hill: The University of North Carolina Press, 2017), 6, 15, 36, 40; Gordon Wood, *The Radicalism of the American Revolution*, (New York: Vintage Books, 1991), 57-63; Michael Oliver & Colin Barnes, *The New Politics of Disablement* (New York: Palgrave Macmillan, 2012), 82; Jacqueline Vaughn Switzer, *Disabled Rights: American Disability Policy and the Fight for Equality*, (Washington D.C.: Georgetown University Press, 2003), 31; Chai R. Feldblum, "Definition of Disability Under Federal Anti-Discrimination Law: What Happened? Why? And What Can We Do About It?", 21 Berkeley J. Emp. & Lab. L. 91 (2000), 94; Michael B. Katz, *In the Shadow of the Poorhouse: A Social History of Welfare in America*, (New York: Basic Books, 1996 [1986]), x, 13-14; Jonathan Levy, *Ages of American Capitalism: A History of the United States*, (New York: Random House, 2021), 57-58; Rabia Belt, "Mass Institutionalization and Civil Death," *New York University Law Review* 96, no. 4 (October 2021): 872-876; Roy Richard Grinker, *Nobody's Normal: How Culture Created the Stigma of Mental Illness* (New York: W.W. Norton & Company, 2021), 66.

[23] Nielsen, *A Disability History of the United States*, 40-47.

[24] Rothman, *Discovery of the Asylum*, 30-31, 41; David Bergner, *The Mind and the Moon: My Brother's Story, the Science of Our Brains, and the Search for our Psyches* (New York: HarperCollins, 2022), 34.

emphasis shifted to the social environment by the early nineteenth century.[25] Mental impairment and dependence on the community was associated with one's social environment and upbringing, rather than the legal system or an individual's innate characteristics. Anonymous individuals who burdened the community were meant to be reformed in the institution, where their environment would be altered to mitigate negative social influences and promote discipline. The cause was the cure: the individual had been molded into a deviant by the social environment, and therefore needed to be reformed through a new social environment. [26]

The new republic of the nineteenth century that allowed for social mobility upward was also considered to be a cause of deviance and abnormality. The emergence of republicanism from the ashes of monarchy altered more than political institutions and relationships, it radically altered social institutions and relationships, too.[27] There was no longer a clear demarcation between aristocrats and dependent laborers, and this new exposure to various choices and opportunities for social mobility was deemed to be a contributing factor for insanity in the United States during the early nineteenth century.[28]

This growing anonymity also contributed to the second major shift in nineteenth century life; as American communities were growing increasingly anonymous, employers and employees were also becoming more anonymous. People did not know personally who they were hiring or firing, these decisions were made based on the appearance of the worker, and differences of appearance would be amplified in this new labor market.

B. Changes in Work and Employment

The second major shift was the development of a new socio-economic order through the rise of industrial capitalism during the second half of the nineteenth century. People's livelihood began to depend on their own individual capacity to engage in industrial labor rather than unique roles and contributions within their communities. Employers wanted interchangeable units of labor, where physically and mentally similar people could be employed and replaced with some predictability of their productive capacities. In this new labor system, uniformity was the ideal and difference was to be avoided.

From the 1840s to the 1920s, the American mode of production wore away at the institutions and environment that allowed for integration of those with impairments into the community. Wage labor based on industrial mechanized production prevented families and communities from supporting their relatives and neighbors with impairments. A structure of production emphasizing top-down centralized management controlled by anonymous employers emphasized the interchangeability of the masses rather than catering particular tasks to unique individuals. This new conception of the independent laborer as capable of performing a variety of manual tasks of industry in a uniform manner excluded those who did not fit that mold. Industrial capitalism's emphasis on efficiency pervaded all aspects of nineteenth century life,

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[25] Rothman, *Discovery of the Asylum*, 62, 68, 109.

[26] Rothman, *Discovery of the Asylum*, 68-69, 71, 76-79, 82, 107; Nielsen, *A Disability History of the United States*, 49-56.

[27] Gordon Wood, *The Radicalism of the American Revolution*, 95.

[28] Rothman, *Discovery of the Asylum*, 116; Gordon Wood, *The Radicalism of the American Revolution*, 8, 24-33, 100-101; J.G.A. Pocock, *The Machiavellian Moment: Florentine Political Thought and the Atlantic Republican Tradition*, (Princeton: Princeton University Press, 2016 [1975]), passim, but especially 333-552.

expanding beyond the workplace to include family life and schooling.[29] Families struggled to support those who were excluded from new work environments, which resulted in many individuals with impairments being placed in institutions.[30] Workers feared treatments and preventative therapies that could temporarily keep them from working, preferring to risk disease rather than admit to disability and inability to work.[31] Laws were passed that that directly targeted "cripples" and "beggars", making it illegal to occupy certain public spaces as a disabled beggar. Ordinances made being disabled and impoverished illegal.[32]

New moral values and assessments developed within this new work environment: work was viewed as a moral virtue that promoted flourishing enterprises and supported families, while idleness was viewed as immoral vice operating as a parasitic drain on the community's socioeconomic wellbeing.[33] The asylums that emerged to address the issue of a portion of the population excluded from the new capitalist order were expected to contribute to this new form of economic production. Although originally founded as philanthropic institutions, the creators and managers of the asylums found that funding from the state was often contingent on the productive capacity of the committed patients.[34]

After the changing mode of production, a second factor that contributed to the conception of disability was the law. Nineteenth century American law understood personhood and citizenship within the image of the white, able-bodied male.[35] This legal understanding manifested throughout American life, as can be seen in workmen's compensation legislation, treatment of veterans after the Civil War and World War I, and immigration law.

The late nineteenth and early twentieth centuries experienced a reconceptualization of the legal treatment of those injured and disabled in the workplace. Nineteenth century common law focused on the injured individual and his or her relationship with their employer. In the first two decades of the twentieth century, workman's compensation laws shifted this focus, emphasizing the generalizable working population based on statistics and actuarial tables. Workplace accidents and injuries had been subject to individualistic inquiry within the context of a

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[29] Douglas C. Baynton, *Defectives in the Land: Disability and Immigration in the Age of Eugenics*, (Chicago: The University of Chicago Press, 2016),60-61, Barbara Young Welke, *Law and the Borders of Belonging in the Long Nineteenth Century United States*, (Cambridge: Cambridge University Press, 2010), 87, 91.

[30] Rose, *No Right to Be Idle*, 50-51, 60, 88, Baynton, *Defectives in the Land*, 56; Roy Richard Grinker, *Nobody's Normal: How Culture Created the Stigma of Mental Illness* (New York: W.W. Norton & Company, 2021), 48.

[31] Rose, *No Right to Be Idle*, 2-3, 111, 122-123, 130-133, 172-173; Karl Marx, *Capital: Volume 1*, (London: Penguin Books, 1990 [1867]), 553, footnote 11, 635, 638, 927-928; Michael Willrich, *Pox: An American History*, (New York: Penguin Press, 2011), 233; Nielsen, *A Disability History of the United States*, 89; Susan M. Schweik, *The Ugly Laws: Disability in Public* (New York: New York University Press, 2009), 47-51, 59-62. Chai R. Feldblum, "Definition of Disability", 95; Robert Drake, "Welfare States and Disabled People," in *Handbook of Disability Studies* eds. Gary L. Albrecht, Katherine D. Seelman, and Michael Bury (Thousand Oaks: Sage Publications, 2001), 415; Katz, *In the Shadow of the Poorhouse*, 5-6, 10; Lennard J. Davis, "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century," in *Beyond Bioethics: Toward a New Biopolitics* eds. Osagie Obasogie and Marcy Darnovsky (Oakland: University of California Press, 2018), 70.

[32] Welke, *Law and the Borders of Belonging*, 57, Schweik, *Ugly Laws*, 16, 59-62; Marta Russell and Ravi Malhotra, "Capitalism and the Disability Rights Movement," in *Capitalism & Disability* ed. Keith Rosenthal (Chicago: Haymarket Books, 2019), 3; Baynton, *Defectives in the Land*, 78.

[33] Rose, *No Right to Be Idle*, 20, 30, 93; Michel Foucault, *Madness and Civilization: A History of Insanity in the Age of Reason* (New York: Vintage Books, 1988 [1965]), 55-60, Grinker, *Nobody's Normal*, 16, 28; Welke, *Law and the Borders of Belonging*, 33, 87.

[34] Rose, *No Right to Be Idle*, 67-82, 94-98.

[35] Welke, *Law and the Borders of Belonging*, 2-3, 6-7.

contractual relationship between employer and employee, but it became an inquiry into risk assessments on a mass scale and group insurance coverage for entire corporations. The rise of industry was inflicting an increasing number of more severe workplace injuries, and the traditional means of integrating those suffering from those injuries into society were no longer capable of helping those in need. The legal understanding of rights-bearing individuals freely engaged in a contract with their employer and assuming the risks of that employment began to fall apart in the late nineteenth century. It would be replaced by new state legislation establishing workmen's compensation laws, which promoted statistical analysis of risk across companies and industries, rather than individual inquiries into particular instances. There was no cause or fault in inherently dangerous work environments, and therefore the outcome was demoralized—no one individual party was to blame, assessments were simply mathematical calculations to provide compensation on a mass scale. Historian Nate Holdren pithily describes this transition from individual-based assessment to workforce-based assessment as a shift from the "Tyranny of the Trial" to the "Tyranny of the Table."[36]

Workmen's compensation statutes disincentivized employers from hiring and retaining workers with impairments. Second injuries and more severe injuries required more compensation, so employers were reluctant to hire those who already had an impairment and might be further harmed by a second and more severe injury. Insurance companies began to charge employers based on the number of accidents in their workplace, which also exacerbated the exclusion of workers with impairments.[37] Workman's compensation statutes not only resulted in the aggregation of a "disabled class" and obfuscation of the individual, they also incentivized employers to purge and exclude workers with impairments from their work force. Human beings were conceptualized as machines that could be swapped out and replaced if damaged.[38]

Judicial opponents of the new workmen's compensation statutes considered them to be an unconstitutional redistribution of private property from one private entity to another (employer to employee, respectively). This understanding shifted slowly and turbulently, with state compensation statutes being ruled unconstitutional and subsequent popular backlash repudiating those decisions. Rather than make constitutional changes at the federal and state levels, reformers advocating for workers compensation statutes altered the statutes themselves to pass constitutional scrutiny—the laws would not take property from employers without providing something to employers, too. The statutes were rewritten and refashioned to allow employers to gain exemption from future liability. Those employers who had insurance plans aligned with the state compensation statute were protected against any future tort liability.[39]

Law and medicine combined to establish new expectations for veterans after World War I. While veterans of the Civil War received pensions, veterans of World War I were expected to rehabilitate after injuries and resume productive work, with orthopedic surgeons explicitly

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[36] John Fabian Witt, *The Accidental Republic: Crippled Workingmen, Destitute Widows, and the Remaking of American Law* (Cambridge, Mass.: Harvard University Press, 2004), 4-5, 12-15, 17, 28, 33-42, 44-49, 63-69 139-145; Claire H. Liachowitz, *Disability as a Social Construct: Legislative Roots*, (Philadelphia: University of Pennsylvania Press, 1988), 51-55; Nate Holdren, *Injury Impoverished: Workplace Accidents, Capitalism, and Law in the Progressive Era* (Cambridge: Cambridge University Press, 2020) 5-6, 80-81.

[37] Rose, *No Right to Be Idle*, 162-164; Marx, *Capital: Volume 1*, 553, footnote 11; Holdren, *Injury Impoverished*, 230-232, 252.

[38] Rose, *No Right to Be Idle*, 171; for the human-machine comparison, see Holdren, *Injury Impoverished*, 224-228, 240.

[39] Witt, *Accidental Republic*, 166-183; Rose, *No Right to Be Idle*, 150.

stating that their surgical interventions were meant to make veterans employable.[40] Benefits were conditional on rehabilitation, and those who failed to rehabilitate were ostracized as burdens on society.[41] The assessment of whether an impaired veteran was successful in their rehabilitation was whether they could regain employment.[42] While the Civil War had marked a shift from individual approaches to actuarial approaches, veterans were eligible for pensions only after receiving a medical assessment.[43] The pension system served as an analogy for worker injuries and disabilities—veterans of war should be afforded the same benefits as veterans of industry.[44] And yet this relationship between perspectives on veteran disability and worker disability was reciprocal: workmen's compensation laws changed the eligibility for benefits and expectations of recipients would change in the early twentieth century. Woodrow Wilson's administration used workmen's compensation laws as a model for rehabilitation of veterans.[45] The War Risk Insurance Act of 1914 insured bodies against harm and injuries from war. It used rating schedules drawn directly from the schedules of workmen's compensation laws. The aim of this law was to push veterans with disabilities back into the work force where they were supposed to resume their gendered role as breadwinners despite injuries and impairments from their time at war.[46]

The development of workmen's compensation laws actually had a severely negative impact on those considered disabled who tried to enter and remain in the work force. In the first two decades of the twentieth century the new workmen's compensation statutes promoted exclusion of those with impairments from the work force and contributed to the construction of disability as a separate dependent class. Dependency was a moral and political issue as reformers and conservatives alike worried that too much aid could lead to a lazy and immoral citizenry.[47]

Another legal process that contributed to the construction of disability as a category was immigration. The history of American immigration has emphasized various justifications for exclusion, such as sex, race, and sexual orientation.[48] Immigration procedures directly linked disability to dependency by categorizing those with impairments as likely to become public charges and therefore subject to exclusion and deportation. Immigration laws from 1882 to 1924 classified disabled immigrants as "lunatics," "idiots," "imbeciles," and "feebleminded," among other labels. At immigration offices immigrants were assessed on their potential capacity for economic productivity in performing their trades; those with impairments were considered to be likely public charges and hence unacceptable socio-economic burdens.[49]

Historian Douglas C. Baynton has argued that disability was the primary concern for immigration officials, and that all other peripheral considerations stemmed from disability:

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[40] Beth Linker, *War's Waste: Rehabilitation in World War I America* (Chicago: The University of Chicago Press, 2011), 49, 60.

[41] Linker, *War's Waste*, 13.

[42] Linker, *War's Waste*, 80-81, 91-94, 96.

[43] Witt, *The Accidental Republic*, 23-24, 149-150; Theda Skocpol, *Protecting Soldiers and Mothers: The Political Origins of Social Policy in the United States* (Cambridge, Mass.: Harvard University Press, 1992), 155-156; Linker, *War's Waste*, 14-15.

[44] Witt, *The Accidental Republic*, 24; Holdren, *Injury Impoverished*, 77-78.

[45] Linker, *War's Waste*, 28.

[46] Linker, *War's Waste*, 30-31.

[47] Rose, *No Right to Be Idle*, 137, 141; Holdren, *Injury Impoverished*, see chapters 4 and 5, generally.

[48] Mai Ngai, *Impossible Subjects: Illegal Aliens and the Making of Modern America* (Princeton: Princeton University Press, 2004), *passim*; Margot Canaday, *The Straight State: Sexuality and Citizenship in Twentieth-Century America* (Princeton: Princeton University Press, 2009), *passim*; Baynton, *Defectives in the Land*, *passim*.

[49] Baynton, *Defectives in the Land*, 94-95; Welke, *Law and the Borders of Belonging*, 58-60.

certain races produced more disability, disease might stem from an underlying disability, sexual deviancy was associated with mental deficiency, criminals were morally disabled, and the poor were mentally inferior. All of these justifications for restriction and exclusion derived from the focal point of disability. Dependence and disability also had a sexist bent, as can be seen in the reasoning behind exclusions of women at immigration offices. Pregnancy was often considered a disability, and unmarried pregnant women were particularly singled out as likely to become a public charge.[50] Given the absolute discretionary power of immigration officials in assessing non-citizens for entry, essentially any deviation from what was considered "normal" could subject an individual to exclusion. Social assumptions of dependence, rather than medical consensus, determined eligibility for entry.[51]

Immigration laws and practices created a collective American consciousness of who was "worthy" and "unworthy" based on productivity, dependence, and ability.[52] Classification and subjugation in the immigration process created a group consciousness among persecuted individuals and their loved ones, which allowed them to consolidate and push back against these oppressive laws.[53] This classification through the immigration process was just one of many legal apparatuses that contributed to the construction of a "disabled" category, as well as the concretization of an activist group that could push back against the laws.

C. The Medicalization of the American People and Their Laws

A third shift that occurred in the nineteenth century that shaped legal understandings of disability in the twentieth century was the rise in medical understandings of the body in the physical world. Breakthroughs in germ theory, formal education and licensing of medical professionals, and the expansion of hospital systems all emphasized empirical observations of the physical world as the foundation of medicine. Throughout the eighteenth and nineteenth centuries, empiricism and physical treatments began to replace religious and moral remedies. Illness and impairments came to be understood as physical and physiological manifestations rather than mystical and spiritual. While this provided advancements for treatments and cures, it also contributed to the categorization of people along strict medical lines. The emerging authority of medical professionals and their influence in the legal sphere was a vital component in creating the legal category that labelled some "disabled."[54]

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[50] Baynton, *Defectives in the Land*, 27, 42-46, 84-85, 93.

[51] Douglas C. Baynton, "Disability and the Justification of Inequality in American History," in *The New Disability: American Perspectives* eds. Longmore, Paul K. and Lauri Umanski (New York: New York University Press, 2001), 45-50; Baynton, *Defectives in the Land*, 13-15, 20-21, 37.

[52] Baynton, *Defectives in the Land*, 135-136.

[53] Welke, *Borders of Belonging*, 105.

[54] Christy Ford Chapin, *Ensuring America's Health: The Public Creation of the Corporate Health Care System* (Cambridge: Cambridge University Press, 2015), 10-14; Paul Starr, *The Social Transformation of American Medicine: The Rise of a Sovereign Profession & the Making of a Vast Industry*. (New York: Basic Books, 2017), 54-55; Michel Foucault, *Madness and Civilization*, 178-181, 269-278; Michel Foucault, *Birth of the Clinic: An Archaeology of Medical Perception* (New York: Vintage Books, 1994 [1963]), xi-xix; Charles E. Rosenberg, *The Cholera Years: The United States in 1832, 1849, and 1866*, (Chicago: The University of Chicago Press, 1987 [1962]), 226-229. Ritchie Robertson, *The Enlightenment: The Pursuit of Happiness, 1680-1790*, (New York: HarperCollins, 2021), 206-210, 427-434; Russell and Malhotra, "Capitalism and the Disability Rights Movement," 4.

i. The Medical Profession

In the late eighteenth century healthcare had not emerged as a profession, it mainly consisted of local family and community treatments and remedies, rather than any specialized approaches by medical professionals. The distinctions based on social classes found in England did not travel across the Atlantic. Instead, physicians, households, and lay healers all shared the medical field at this time.[55] No one social class dominated medicine: it was accessible to all walks of life, in part because it had to be. Small, isolated communities had to address health issues any way they could, without a more centralized, formal apparatus governing standards and practices. At the beginning of the nineteenth century Americans were more independent and self-reliant, but by 1900 Americans had begun to surrender more authority over medical care to professionals who had developed specialized expertise. This authority developed in part due to the rise of educational institutions and state licensing requirements.[56]

From 1873 to 1910, there was a dramatic increase in the number of hospitals as urban life and industrialization altered the American socio-economic environment so that families began to look to hospitals and clinics for care, rather than domestic methods. Throughout the Gilded Age and Progressive Era the medical profession widened the social distance between doctor and patient. The profession became more uniform and specialized, resulting in higher pay across a cohesive class of practitioners.[57] State licensing of medical education institutions and health care providers solidified this coalescence of the profession, and the Supreme Court affirmed this centralization through licensing in the cases of *Dent v. West Virginia*, which upheld the state's ability to license as long as requirements applied to everyone, and *Hawker v. New York*, which allowed states to take into consideration the character of the physician when licensing.[58] A major force contributing to licensing and educational requirements was the American Medical Association (AMA). Formed in 1847, the AMA sought to control the licensing and education process, even going so far as to unite with former adversaries to push for state-recognized licensing.[59] This led to centralization around the AMA as a bestower of accreditation for medical institutions and practitioners.[60] The AMA began to classify medical schools into a taxonomical and hierarchical structure, and states relied on it to determine whether an institution was providing acceptable and legitimate training for students seeking to earn licenses.[61] This shift also contributed to the social stratification of physicians. As education became more rigorous and difficult to attain, the supply of expertise decreased. Physicians entered a new socioeconomic class as their services brought in more money through an increase in demand.[62] Scientific advancements such as germ theory and vaccinations, along with these institutional

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[55] Paul Starr, *The Social Transformation of American Medicine*, 30-40.

[56] Paul Starr, *The Social Transformation of American Medicine*, 18-20.

[57] Christy Ford Chapin, *Ensuring America's Health*, 11-2; Paul Starr, *The Social Transformation of American Medicine*, 72-75, 79-81.

[58] Paul Starr, *The Social Transformation of American Medicine*, 102-112; Robert J. Gordon, *The Rise and Fall of American Growth: The U.S. Standard of Living Since the Civil War* (Princeton: Princeton University Press, 2016), 50, 208, 224-226.

[59] Christy Ford Chapin, *Ensuring America's Health*, 10; Leslie J. Reagan, "Law and Medicine," in *The Cambridge History of Law in America: Volume III*, eds. Michael Grossberg and Christopher Tomlins. (New York: Cambridge University Press, 2008), 233; Paul Starr, *The Social Transformation of American Medicine*, 98-102.

[60] Christy Ford Chapin, *Ensuring America's Health*, 10-11; Willrich, *Pox*, 258-259; Paul Starr, *The Social Transformation of American Medicine*, 109-110.

[61] Paul Starr, *The Social Transformation of American Medicine*, 109-121.

[62] Paul Starr, *The Social Transformation of American Medicine*, 124-127.

developments, led to a professional and specialized class of medical practitioners at the dawn of the twentieth century.[63]

The alliance between state governments and the AMA for licensing accreditation was an early instantiation of what would be the norm in twentieth century American health care—closely connected and symbiotic relationship between state institutions and the private sector. State oversight and affirmation of medical coverage and professional licensing was just the start of a wider, federal move toward intervention in healthcare. The processes of centralization and federal intervention in healthcare coverage and welfare were accelerated with the rise of the administrative state after the New Deal.[64] This expansion of the state and federal role in healthcare would contribute to the generation of a legal category of disability at the federal level.

ii. Medicalization and Law

This strengthening emphasis on medicalization became manifest in law through judicial decisions and legislation. These decisions grappled with medical assessments of people and determinations of risk to individual and public health. Vaccine mandates and eugenics were both areas where law and medicine became more intertwined in the nineteenth and early twentieth centuries.

One intervention of medicalization into law was the passage of vaccine mandates and their affirmation of constitutionality by the Supreme Court in *Jacobson v. Commonwealth of Massachusetts*.[65] Massachusetts had passed a vaccine mandate which imposed a five dollar fine on those who did not get vaccinated or obtain an exemption through a physician's note. Henning Jacobson refused to be vaccinated and pled not guilty, arguing that the statute was unconstitutional under the Fourteenth Amendment. The Court ruled that the mandate was constitutional and a justified exercise of police power within the jurisdiction of the state.

On a broad level, vaccine mandates were the beginning of the rising administrative state and the intervention of federal government into medicine and localities.[66] As smallpox began to break out in various counties and towns across the United States, the role the federal government could play in providing aid was unclear. The federal government, in the form of the U.S. Marine Hospital Service, began to educate and inform different parts of the country about smallpox and assess health threats. From 1890-1910 towns and cities across the United States called on the federal government for aid during smallpox outbreaks.[67] The expertise of federal officials and the dire need of local communities during these dangerous outbreaks resulted in the extreme situation of the federal government exercising police power at the local level.[68] Vaccine mandates and federal aid prompted questions of state and federal power at the turn of the twentieth century, and their respective jurisdictions in a new medicalized world.

Another area where medicalization was injected into law was eugenics. Medical understandings of who was "normal," or even "superior" in American life became manifest in law, notably through the infamous case of *Buck v. Bell*.[69] The esteemed Justice Oliver Wendell

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[63] Christy Ford Chapin, *Ensuring America's Health*, 15; Leslie J. Reagan, "Law and Medicine," 238-239; Paul Starr, *The Social Transformation of American Medicine*, 134-135.

[64] Karen M. Tani, *States of Dependency: Welfare, Rights, and American Governance, 1935-1972* (Cambridge: Cambridge University Press, 2016), 3-10.

[65] 197 U.S. 11 (1905).

[66] Willrich, *Pox*, 14.

[67] Willrich, *Pox*, 42-65

[68] Willrich, *Pox*, 74, 88-89.

[69] 274 U.S. 200 (1927).

Holmes, Jr. wrote one of the most notorious opinions in American legal history, in which he ruled that sterilization statutes based on eugenics were constitutional. This decision represented a fear rife in the United States that those considered disabled would overwhelm and weaken the nation.[70] Sterilization laws were justified as within the states' police powers to protect the health, safety, and welfare of the people.[71]

Eugenics and conceptions of disability also fused with racism to justify antebellum slave laws. African Americans were subjected to slave laws and oppression because racist institutions considered them to be intellectually inferior and lacking in character. Racist defenses of these oppressive laws argued they were merely reflections of biology. Before the Civil War slaves suffered from inhumane medical interventions, and after emancipation freedmen continued to struggle with health crises. The subjection slaves experienced was so insidious and pervasive that just meeting with others outside the purview of the slaveowner was considered "theft" of time and space that was often punished with violent beatings and death.[72] This dehumanization was also present in medical treatment. Medical professionals treated similar medical issues differently depending on the race of the individual they were treating. A Georgia physician explicitly stated as much when he amputated a fifteen-year-old slave girl's leg without making efforts to treat the minor injury with less-invasive measures, saying "[Amputation] should be very differently estimated in the different classes of society." He went on to state that while amputation should be the last resort for a wealthy white man, it was "'a matter of comparatively little importance'" for a slave. When slaves were sent to hospitals by their owners, doctors would use far more serious interventions like amputation to practice the procedure and show students how to perform it.[73] During Reconstruction local authorities would not provide resources to treat illnesses for newly freed black Americans, and white doctors would refuse to treat them.[74] Gynecologists also experimented on black women during pregnancy and subjected them to pain and suffering to further their medical knowledge.[75] From slavery to medical conceptions of inferiority, law and medicine clearly worked together to subjugate African Americans during the

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[70] Welke, *Borders of Belonging*, 118-119.

[71] Welke, *Borders of Belonging*, 134-135; Switzer, *Disabled Rights*, 36-38. For example, see Henry Gibbons's sentiments during his address to the San Francisco Medical Society in 1869: "A large infant mortality growing out of neglect, rids the flock of the most feeble and sickly individuals, and leaves a higher standard of health to the rising generation. On the other hand, if the utmost care were exercised to rear up to adult life all infants with feeble or depraved constitutions, it is evident that their admixture with the common stock as parents would lower the average health of the next generation. This is a well established law. The husbandman observes it when he kills the feeble and dwarfish, and spares the strong and vigorous of his herd. It applies as strictly to the human household as to the farm-yard." Henry Gibbons, "Annual Address before the San Francisco Medical Society," November 9, 1869, by in UCSF Library: Archives and Special Collections, Henry Gibbons Papers, MSS 73-5.

[72] Saidiya V. Hartman, *Scenes of Subjection: Terror, Slavery, and Self-Making in Nineteenth-Century America* (New York: Oxford University Press, 1997), 65-70.

[73] Harriet A. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (New York: Anchor Books, 2006), 108-109.

[74] Eric Foner, *Reconstruction: America's Unfinished Revolution* (New York: HarperCollins, 1988 [2002]), 151.

[75] Deirdre Cooper Owens, *Medical Bondage: Race, Gender, and the Origins of American Gynecology* (Athens, GA: University of Georgia Press, 2017), *passim*; Keith Wailoo, "Historical Aspects of Race and Medicine: The Case of J. Marion Sims." *Journal of the American Medical Association* 320, no. 15 (2018), 1529-30.

nineteenth and early twentieth centuries.[76] Disparities in medical treatment would continue well into the twentieth and twenty-first centuries.[77]

Vaccines and eugenics were just two examples of an increasingly medicalized American society and legal system at the turn of the twentieth century. Private providers and physicians would merge their expertise with federal and state legislation to create a codified legal category of disability in the twentieth century.

D. Conclusion

These three shifts—social anonymity, labor uniformity, and institutionalized medicine—all contributed to the conception of disability as tied to work. In the twentieth century, American law and health care would strive to address those considered dependent and unable to work. When allocating benefits or determining whether discrimination on the basis of disability was present, the legal system would need to make assessments about unknown individuals with limited information, in the context of a "normal" and "model" worker, with the help of medical expertise.

II: The Twentieth Century and the Federal Legalization of Disability as a Category

In the early twentieth century, disability was defined according to the trends newly established, whereby employers and state institutions began to make medical assessments of anonymous individuals within the context of a uniform work force. Those who were deemed medically different and incapable of producing within this new uniform understanding of labor were then considered "disabled" dependents in need of assistance. The problem of how to care for the "disabled" was an issue with which twentieth century private and public institutions would grapple.

During the twentieth century, American healthcare shifted from an atomized, decentralized system to one that was more centralized and structured. There was a new conception of disability in an anonymous society with a uniform labor force and medicalized understandings of the body. American law grappled with how those considered disabled could be employed, and how those who were not employed in this system could sustain themselves.

With the rise of the administrative state in the twentieth century, two key dynamics shaped American health care and how it would meet the needs of those considered disabled. The first was the relationship between the public and private sectors in efforts to provide health care to Americans. In the 1930s and 1940s there emerged a hybrid public-private system, a key aspect of which was that each sector covered different people. The private sector primarily covered the

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[76] Welke, *Borders of Belonging*, 131-132; Sabrina Strings, *Fearing the Black Body: The Racial Origins of Fat Phobia* (New York: New York University Press, 2019), 179.

[77] For how these disparities continue in modern medicine, see, for example, Dayna Bowen Matthew, *Just Medicine: A Cure for Racial Inequality in American Health Care* (New York: New York University Press, 2015), *passim*, discussing the effects of unconscious bias in medical practices negatively impacting African American patients. For the Tuskegee study failing to treat African Americans experiencing syphilis, see Reagan, "Law and Medicine," 255-256; David J. Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (New York: Basic Books, 1991), 183; Susan M. Reverby, ed., *Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study* (Chapel Hill: UNC Press Books, 2012), *passim*.
Susan Reverby also explores the active infection of individuals outside the borders of the United States in Susan M. Reverby, "'Normal Exposure' and Inoculation Syphilis: A PHS 'Tuskegee' Doctor in Guatemala, 1946-1948," The Journal of Policy History, Vol. 23, No.1, 2011. In Guatemala from 1946-1948, the Public Health Service actively infected individuals with syphilis, unlike the Tuskegee study where African Americans had syphilis but were left untreated.

young and healthy, who were more likely to provide returns for insurance companies; the public sector primarily covered the most vulnerable, and therefore the more costly. This meant that the public sector had to develop means by which it could provide for those who often could not contribute to the uniform work force and "earn" their benefits through a traditional insurance model. The second dynamic was the relationship between the states and federal governments, and how each addressed this problem left to the public sector. Two solutions developed to address the problem of caring for the uninsured who were excluded from the work force: welfare benefits and vocational rehabilitation. First, welfare benefits were funded by the federal government and administered by the states, leading to various different approaches depending on the state in which the individual considered disabled resided. Second, vocational rehabilitation was meant to mend "broken" workers and return them to the work force.

Eventually, starting in the 1970s, antidiscrimination statutes would emerge from a new awareness of disability as an environmental and social issue, rather than a problem with the individual considered disabled. This new perspective on how to understand disability as an issue with the environment, rather than the person, was in large part a result of the Disability Rights Movement in the 1960s and 1970s. Starting with §504 of the Rehabilitation Act of 1973—a precursor for the Americans with Disabilities Act of 1990—federal law began to enforce antidiscrimination provisions on the basis of disability against public and private employers. For those who did not work, welfare benefits were provided, while for those who felt they could work, but were being prevented from doing so, antidiscrimination statutes allowed them to challenge discriminatory employers and workplace environments that prevented them from engaging in the labor force.

A key component of each was the medicalization of legal definitions of disability. For welfare benefits, means tests often required medical documentation of the disability for eligibility. For vocational rehabilitation, medical documentation was the declaration of ability or inability to work. Later, even antidiscrimination statutes would often require medical documentation to be provided as dispositive evidence of an individual's need for accommodation or that an employer did discriminate on the basis of disability.

These approaches tackled different aspects of aiding those considered disabled: disability benefits aided those who were completely excluded from the work force, while vocational rehabilitation was meant to retrain the individual to rejoin the labor force. Disability benefits were the result of an emerging federal administrative state that sought to provide security for those in need during the 1930s. The allocation of these benefits would call into question the responsibilities and duties of the public and private sectors, as well as the jurisdictions of the state and federal government. Antidiscrimination statutes were passed in the 1970s and 1990s to address the burdens placed on those considered disabled who could still work but were impeded from doing so by obstacles in the workplace environment. The second part of this section will discuss the legal development of disability benefits and vocational rehabilitation services.

A. The Subsidized Private Sector and Public Coverage for High-Risk Individuals

A major factor contributing to the failure of compulsory public health insurance throughout American history is the symbiotic relationship between private and public healthcare coverage. At vital definitive moments in the development of American healthcare, public and private entities have converged to create a hybrid system that resulted in a private voluntary health insurance system heavily subsidized and supplemented by public resources. The suppression of compulsory public health insurance and the rise of voluntary private health insurance has been a product of government regulation, tax policies, and state subsidization. State construction of a private arm covering health care early set the United States on a path that would be difficult to leave. After early decisions were made that created a hybrid public-private system, it became politically infeasible to deviate from that trajectory. Americans have come to understand and accept the private sphere's role in health care without questioning how public resources have contributed to it. The history of American healthcare demonstrates this formation was politically created at key moments, especially in the New Deal and post-World War II era, pushing the United States along this path despite the availability of other options. This public-private hybrid formation of American healthcare was not an inevitable outcome, but instead a product of political decisions at key moments in the development of the health care system.[78]

The private sector did not simply obstruct the development of state-based compulsory coverage. It pushed against state involvement at times when it was viewed as a threat but offered concessions at times when overwhelming forces were surmounting its resistance. When it conceded, the private sector would often push for state-based coverage that would actually improve its position, rather than harm it. During the Progressive Era, the American Association for Labor Legislation (AALL) campaigned for compulsory health insurance, but lobbying by private insurers and physicians through medical societies overcame a labor movement divided on the issue.[79] Despite gains made toward centralized federal health care coverage during the 1930s and 1940s, the private sector's concessions allowed it to cover the healthy and avoid coverage of the most vulnerable, leaving that responsibility to the public sector.[80] Even the Great Society's gains in the 1960s that allowed for more health care coverage for the elderly in Medicare and funding for state programs to address some health care needs for those who passed means tests still provided extravagant fees for providers, especially before prepayment models developed. These two amendments to Social Security again allowed for the private sector to engage in adverse selection by ensuring the state would provide coverage for the least vulnerable.[81]

At these points of major importance in the development of American health care—the Progressive Era, the New Deal, and the Great Society's innovations in Medicare/Medicaid—the private sector maintained influence and involvement in the American health care system. The dual spheres of public and private coverage did not operate separately; public mechanisms of coverage often operated *through* private coverage in the form of subsidization and regulation.[82] The relationship between private and public sectors was thus reciprocal—while the public sector subsidized the private sector, and the private sector influenced state social policy.[83] However, as health care coverage and benefits shifted to the private sector through employers, it moved away from political influence and accountability. As coverage was privatized, the public lost political autonomy and oversight. Employers provided welfare benefits through government

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[78] Jacob S. Hacker, *The Divided Welfare State: The Battle Over Public and Private Social Benefits in the United States* (New York: Cambridge University Press, 2002), 7-12, 18, 26, 52-54, 60-61 180, 188; Jennifer Klein, *For All These Rights: Business, Labor, and the Shaping of America's Public-Private Welfare State* (Princeton: Princeton University Press, 2003), 78-79, 85-88, 234-235, 268.

[79] Hacker, *Divided Welfare State*, 195-196; Jennifer Klein, *For All These Rights*, 26; Jill Quadagno, *One Nation, Uninsured*, 19-21.

[80] Hacker, *Divided Welfare State*, 95, 103; Klein, *For All These Rights*, 78-79; Quadagno, *One Nation, Uninsured*, 22-23.

[81] Hacker, *Divided Welfare State*, 327-330; Quadagno, *One Nation, Uninsured*, 100-104; Stevens and Stevens, *Welfare Medicine in America*, 108, 117, 121, 183.

[82] Hacker, *Divided Welfare State*, xiii; Klein, *For All These Rights*, 5, 202, 204.

[83] Hacker, *Divided Welfare State*, 23.

subsidization. They are able to control how those benefits were allocated, all the while receiving credit for providing them.[84]

A major outcome that developed from this public-private relationship has been private coverage of low-risk individuals and public coverage of high-risk individuals. Rather than operate as a competitive threat against private insurers, forms of public insurance have often served as alleviation of expensive, high-risk coverage for private insurers. The War Risk Insurance Act of 1918, which created a federal system of life insurance subsidized by the government, was an early example of the government subsidizing particularly risky individuals in need of insurance and protecting private commercial insurers from higher risk clients. The federal government would do so again throughout the twentieth century. The development of old-age pensions in the Social Security Act, for example, served as a boon for private employers' pension funds, which could now focus on higher-earning employees and not have to worry about lower-wage employees who were now covered by a federal pension. The federal government had provided a pension floor for all workers, upon which private employers could entice higher earners with pension packages on top of that preexisting federal floor.[85] The Social Security Act further supplemented private plans through the 1939 Amendments, which provided tax exemptions for employer payments to employee benefit plans.[86] In the 1960s, the federal government again assumed the care of individuals who were more at risk and costly to private insurers through Medicare and Medicaid.[87]

This relationship between the public and private sectors was crucial in creating a legal category of disability. Between the two sectors, private entities were able to cover the healthier employed worker that would lead to higher profits, while public state entities were left to cover the most vulnerable and those most likely to be excluded from the work force. As public entities began to take on this responsibility, a new dynamic emerged that would define the legal category of disability—the allocation of duties between the states and federal governments.

B. Federalist Division of Public Coverage: Spheres of State and Federal Control

From the military pensions after the Revolutionary War to modern perceptions distinguishing between the deserving recipients of Medicare insurance and the undeserving recipients of Medicaid coverage, American law and healthcare coverage has grouped certain individuals as "deserving" and "worthy" of coverage. Others deemed "unworthy" based on their supposed capacity for work but lack of employment were often excluded from welfare programs. This section will analyze how the federal government and states allocated resources based on this distinction.

Although the emphasis in federal healthcare prior to the New Deal focused on military pensions, there were still federal efforts to provide certain categories of people with healthcare. Ten years before the New Deal, the federal government was taking steps toward public health care coverage. In 1920, the Sterling-Lehlbach Act established a pension system for federal civil servants, and a year later, the Sheppard Towner Maternity and Infancy Act was the first federal social welfare program in the United States, providing federal matching grants for measures meant to reduce infant mortality and protect the health of mothers.[88] In 1933, the Townsend Plan

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[84] Hacker, *Divided Welfare State*, 44, 50; Klein, *For All These Rights*, 182-183, 228.

[85] Hacker, *Divided Welfare State,* 102-103; Béland, *Social Security*, 115.

[86] Klein, *For All These Rights*, 111.

[87] Hacker, *Divided Welfare State*, 92, 250.

[88] Béland, *Social Security*, 59-60.

proposed a federal pension that would provide citizens aged sixty or over with $200 per month under the condition that they leave the work force and spend that money by the end of each month. However, this plan was not supported by Roosevelt, who wanted more ambitious social insurance programs.[89]

These limited social insurance programs preceded the first major intervention by the federal government into healthcare coverage and welfare benefits–the Social Security Act (SSA). Passed and signed into law on August 14, 1935, the SSA provided decentralized unemployment insurance, a federal old age insurance program, and grants for states to provide resources to the elderly and families.[90] Like the military pensions and Sheppard Towner Act, the SSA was a manifestation of the "deserving" and "undeserving" distinction when providing resources at the federal and state levels. An emphasis was placed on those considered *incapable* of working, such as the elderly, rather than all Americans regardless of age. The SSA was one statute among many that began to centralize control of welfare benefits, moving them from a local issue to a federal one.[91]

The inclusion of health insurance in the SSA was considered, but ultimately it was left out. Some scholars have attributed this to the medical profession's opposition, especially in the form of the AMA, but while this was a relevant factor, it was not the only factor. Internal divisions and conflicts within government agencies also stymied efforts towards universal compulsory insurance, and a resurgence of conservative power at the federal level in 1938 made any political solution less feasible. [92]

The 1939 Amendments added a mechanism to the SSA for income redistribution. Although benefits were still derived from the payroll tax, the 1939 Amendments included a gendered scheme of spousal and survivor benefits, increasing benefits for traditional couples without increasing benefits for single individuals. The 1939 Amendments covered dependent spouses and widows, children under 18 years of age, and aging parents.[93]

Government benefits for the disabled had three major features in the second half of the twentieth century. First, they were a continuation of the distinction between worthy and unworthy categories for those in need. Those who received benefits that they had not "earned" through regular deposits were subjected to rigorous means tests. Second, they were largely state-based; states exercised wide discretion after meeting basic requirements for federal approval of Medicaid plans. Third, they were strictly monitored and culled for fiscal efficiency. Extra costs going into these programs were often considered wasteful and irresponsible spending.

Disability coverage for mothers, children, and infants was included in the original passage of the SSA in 1935, and attempts made in 1943 to cover temporary disability, but it was not until the 1950s that federal coverage of disability insurance for workers would be introduced as part of Social Security.[94] The first federal effort to address disability on a large scale explicitly came with the amendments to the SSA in the 1950s. Starting in 1950, Congress passed a welfare program to address those who were deemed "permanently and totally disabled," which provided states with funds to formulate their own programs for allocation of funds to those who could

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[89] Béland, *Social Security*, 69-72; Pratico, *Eisenhower and Social Security*, 3-4.

[90] Béland *Social Security*, 94. Starr, *Social Transformation*, 266-270; Quadagno, *One Nation, Uninsured*, 23.

[91] Tani, *States of Dependency*, 29, 50-56.

[92] Pratico, *Eisenhower and Social Security*, 8-9; Quadagno, *One Nation, Uninsured*, 23; Starr, *Social Transformation*, 275-279.

[93] Béland, *Social Security*, 97-98, 106-107; Pratico, *Eisenhower and Social Security*, 12-13; Witt, *Accidental Republic*, 200.

[94] Starr, *Social Transformation*, 270; Béland, *Social Security*, 118; Pratico, *Eisenhower and Social Security*, 15.

demonstrate their need.[95] In 1954, Eisenhower signed into law PL 83-761, which froze wages for those disabled and provided vocational rehabilitation programs through individual state agencies, while states retained the ability to make eligibility determinations.[96] Two years later, Social Security Disability Insurance (SSDI) was passed into law as a gap filler for those who did not qualify for workers' compensation. This federal program provided funding to state agencies to administer the program, leaving states with discretion over the allocation of benefits. It provided financial support to those who had paid into Social Security but had a disability that prevented them from working. When making determinations for disability insurance, the Social Security Administration's guidelines to the states took into consideration age, education, and sex; and perhaps most importantly, the individual's economic environment.[97]

Both the 1954 and 1956 measures addressed disability within a context of work and dependence. Both left eligibility determinations to the states. To obtain the benefits of these laws, claimants had to show they could not work due to a medical impairment. The 1954 law provided frozen wages and rehabilitation with the understanding that the person had wages that could be frozen and could be rehabilitated to return as a productive member of the work force. The SSDI legislation considered the individual's capacity to work based on the environment they were in—were there jobs available in the region? Did those jobs have certain physical or mental requirements that precluded the individual from doing them? These laws in the middle of the 1950s established the concept of disability as tied to work and dependence into the American legal system.

State-based allocation of government benefits in the 1950s carried over into the 1960s with the predecessor of Medicaid, the Kerr-Mills legislation, which passed in 1960. The Kerr-Mills Act was an extension of an existing system of vendor payments to states, so that state governments retained control of eligibility determinations for welfare benefits. Medicaid was an amendment to the Social Security Act that essentially operated as an expansion of Kerr-Mills, as stated explicitly in the Senate report on Medicaid.[98] States submitted their plans for medical assistance to the Department of Health, Education, and Welfare, which would either approve or reject that plan. These plans had to meet basic standards to be accepted: they had to apply to all parts of the state, they had to provide the opportunity for all potential recipients to apply for services, and each state had to establish an agency to administer that plan. This rather low baseline of requirements allowed vast discretion at the state level, resulting in stark differences in health care for those receiving Medicaid benefits in different states.[99]

Both the Kerr-Mills legislation and Medicaid were a perpetuation of the distinction between the deserving and undeserving poor. As dependence became tied to working within a uniform labor force, those who did not fit this mold became subject to assessments to distinguish

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[95] Berkowitz, *Disabled Policy*, 70; Tani, *States of Dependency*, 173.

[96] Pratico, *Eisenhower and Social Security*, 30-31, 39, 48-49; Berkowitz, *Disabled Policy*, 74.

[97] Berkowitz, *Disabled Policy*, 41-46, 77; Feldblum, "Definition of Disability," 97; Quadagno, *One Nation, Uninsured*, 54-55; Switzer, *Disabled Rights*, 52.

[98] Stevens and Stevens, *Welfare Medicine in America*, 51.

[99] Laura D. Hermer, "Federal/State Tensions in Fulfilling Medicaid's Purpose," 21 Annals Health L. 615 (2012), 618-619; Nicole Huberfeld, "Post-Reform Medicaid before the Court: Discordant Advocacy Reflects Conflicting Attitudes," 21 Annals Health L. 513 (2012), 443-449; Jane McCahill & Joseph T. Van Leer, "The Challenges of Reform for Medicaid Managed Care," 21 Annals HEALTH L. 541 (2012), 548; Jamila Michener, *Fragmented Democracy: Medicaid, Federalism, and Unequal Politics*, (Cambridge: Cambridge University Press, 2018), 8, 13; Sara Rosenbaum, "Medicaid at Forty: Revisiting Structure and Meaning in a Post-Deficit Reduction Act Era," 9 J. Health Care L. & Pol'y 5, 35-46 (2006), 8-16; Stevens and Stevens, *Welfare Medicine in America*, 28-29, 32, 58-59.

the "deserving" from the "undeserving." An individual considered disabled was subject to stricter eligibility requirements or excluded from benefits entirely. Earlier in the century, benefits had been allocated to mothers and children deemed incapable of caring for themselves. In the 1950s, those who were categorized as medically incapable of working joined mothers and children.[100] This trend continued with Medicaid, which only provided healthcare benefits to certain categories of individuals. State Medicaid plans had to provide welfare benefits to those considered "categorically needy" under Kerr-Mills. These included Old Age Assistance, Aid to the Blind, Aid to Families with Dependent Children, and Aid to the Permanently and Totally Disabled. Beyond cash assistance, Medicaid expanded coverage of medical bills for the medically indigent who passed a means test based on income.[101]

States had to provide certain services in their Medicaid plans: inpatient and outpatient hospital services, laboratory and x-ray services, nursing home services, and physicians services in hospitals, nursing homes, and elsewhere. Outside of these mandatory services, states could provide optional services that would be reimbursed through federal funding, such as home health care services and private nursing care. A major issue that arose for Medicaid during its implementation was cost control. Backlash struck quickly after it passed, as critics at the state levels and in Congress began voicing concerns over rising expenses.[102]

There was a nearly twenty-year gap between the original Social Security Act in 1935 and amendments addressing disability in the 1950s. During those twenty years, options at the state level would prove crucial. The state's health care options and resources available to those with a limited capacity to work would be all the more important because of the absence of federal alternatives. Navigating the interplay of public health care systems, especially county hospitals, and private health care systems, such as practicing physicians' offices and the emerging prepayment group plans would be pivotal for those seeking care.

Conclusion

This chapter has shown how the legal concept of disability developed over the nineteenth and twentieth centuries and became codified in law, creating the legal landscape in which Californians with disabilities would find themselves in the middle of the twentieth century. In the nineteenth century, increased population and urbanization meant those once care for within families and local communities became anonymous inhabitants of cities. Industrialization emphasized the importance of a replaceable, uniform worker. Medicalization promoted assessments by medical doctors to determine an individual's capacity to work. In the twentieth century, the private-public divergence of health care created a two-tiered system: young, healthy, and employed workers were covered by private insurers, while older, impaired, and unemployed individuals were either not covered at all or received some federal or state benefits. The federal split between national government and state government created a patchwork system for the impaired and unemployed seeking benefits. After providing some coverage of certain groups (such as veterans, mothers, and children) the national government began to provide benefits on a larger scale through amendments to the Social Security Act in 1954 and 1956. In the 1960s, Medicare, and especially Medicaid gave more tools to states to provide care for individuals with disabilities. However, these programs emphasized medical evaluations and capacity for work in determining eligibility.

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[100] Stevens and Stevens, *Welfare Medicine in America*, 43.
[101] Stevens and Stevens, *Welfare Medicine in America*, 57, 61, 63.
[102] Stevens and Stevens, *Welfare Medicine in America*, 66, 86-87, 91.

This was the context in which activists would challenge the legal definition of disability and advocate for a new framework placing the onus on society to change through accommodations, rather than on the individual to change through vocational rehabilitation. In the middle of the twentieth century those with disabilities essentially had two options: vocational rehabilitation to become employed or receive benefits. Disability activists were not satisfied with these two options, they would attempt to reframe the concept of disability to add a third option: accommodations that altered the environment to make it more accessible for all people.

In California in the 1930s all these tracks would converge. Disability's medical definition as a capacity to work based on anonymous medical evaluations would impact access to quality health care for individuals who were considered disabled. Private, employment-based health care would dominate the market and become more affordable for those who worked. The public options available to those deemed incapable of working were limited to public health care systems, and the funding for those systems would decrease as private practitioners expanded and increased their share of the market.

Chapter 2: Scorching Earl Warren's "Third Frontier": The Private Creation of "Disability" as a Public Category

> "The third frontier of public health that still requires our attention and the utmost of our effort is the problem of the permanently disabled. The first approach has been to provide minimum cash benefits during periods of disability, but the more fundamental solution must be to restore as many of the disabled to productive and happy lives as may be possible through the combined efforts of science and government." Earl Warren in San Francisco, California, October 30, 1951.[103]

In March 1937, Dr. Juliet Thorner arrived in Bakersfield, California to start a new job at Kern County General Hospital. She had been trained at Stanford Medical School and the Los Angeles Children's Hospital. After recuperating from an illness in Santa Barbara she was invited by a family friend and radiologist to start a pediatric practice in the Central Valley. Reminiscing about her arrival, she said, "I found out that the joy experienced by the then attending staff was not because of my charm, my wit, my knowledge or my skill, but was the fact that I was flesh. There was one more body that would be able to take first calls." The hospital was under-resourced and dealing with severe illnesses suffered by impoverished farm workers. Immediately, Thorner became responsible for the pediatric outpatient clinic and the inpatient pediatric patients, as well as all newborns. In addition to those duties, she was also first on call for the entire hospital every fifth night. Overworked, underpaid, and treating too many patients with major medical problems, Thorner could not cope, and left after just six weeks. It took a doctor from the Public Health Department, Al Sox, to convince her to go back. She was persuaded by his argument that it was a learning experience, and that the overwhelming workload was an essential part of her training.[104]

During her time at the hospital, Thorner became close with a bright young boy she called J.C. Smith (that was not his real name). In the early 1940s he was brought in by his family on a jalopy from Barstow with a complaint of weakness in one arm. Thorner could not figure out what the ailment was, so she sent him to a specialist visiting from Los Angeles. The specialist performed an operation but the boy did not improve, and was then sent to Stanford where he was diagnosed with a rare degenerative condition called syringomyelia. His condition slowly worsened, affecting his feet, his back, and eventually his speech. He had always dreamed of working as a real estate agent because as Thorner said, "he could sell anybody anything." But an individual could not get a real estate license without having first worked in a real estate office, and no real estate office would hire him as an intern because of his condition. J.C.'s problem was

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[103] Earl Warren, "Public Health: Address to the National Convention of the American Public Health Association," in *The Public Papers of Chief Justice Earl Warren* ed. Henry M. Christman (New York: Simon and Schuster, 1959): 36-37.

[104] Juliet Thorner, M.D. "California Odyssey: The 1930s Migration to the Southern San Joaquin Valley," an oral history conducted by Michael Neely, Oral History Program, California State College, Bakersfield, 2-6.

a microcosm of the tight relationship between health care, disability, and employment that would plague Californians who were considered disabled throughout the twentieth century.[105]

Thorner's harsh working conditions, the medical desperation of her patients, and the plight of J.C. Smith in particular were not the result of personal misfortune or some tragic accident beyond anyone's control. Instead, they were direct products of California state legislation and judicial decisions. Just a year prior to Thorner's arrival in Bakersfield, for example, the California judiciary had arrived at a decision that limited the funding and resources available to county hospitals.[106] Her conditions of work in a public hospital were directly imposed on her by the California state legal system.

This chapter shows how a concerted effort by professional medical associations and private providers used state legislation and judicial decisions to create a two-tiered health care system in California, in which those like J.C. Smith, disabled and with few resources, were forced into limited public care while those considered abled and with sufficient means to pay for medical services were funneled into private care. The chapter traces the evolution of California health law and the impact of legal institutions in limiting and categorizing health care coverage. Professional associations intentionally created a legal schism through litigation at the state level by pushing employed and able-bodied patients with means to pay towards the private sector while foreclosing public, less expensive options that had been available to all Californians. Patients without employment, considered disabled, and with limited resources were left to the underfunded and overcrowded state facilities.

The compartmentalization of people into distinct types of care is particularly important during the 1930s and 1940s because it took place amid dramatic improvements in medical care. Prior to the twentieth century, care from physicians had a negligible impact on patients, and could in fact be harmful. Toward the end of the nineteenth century, however, medical education improved significantly with the development of institutions devoted to educating physicians and training them in modern techniques.[107] In the first few decades of the twentieth century technological advances and new knowledge greatly improved medical services, such that time with physicians could provide vital lifesaving and life-extending care.[108] Improvements in technology and expertise did not, however, make medicine cheaper and more accessible. On the contrary, costs rose. Howard Hassard, a lawyer for the California Medical Association who was its general counsel from 1945 to 1987 and its executive director from 1958 to 1967, claimed that improvement in care and decrease in costs were diametrically opposed. He argued that medicine

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[105] *Id.*, 15-16.

[106] *Goodall v. Brite*, 11 Cal. App. 2d 540 (1936).

[107] Henry Gibbons, *Some Defensive Remarks on the Medical Education and Medical Schools of America, and particularly California* (San Francisco: Bonnard and Daly, Printers, 1877) in UCSF Library: Archives and Special Collections, Henry Gibbons Papers, MSS 73-5, 30-34; Leslie J. Reagan, "Law and Medicine," in *The Cambridge History of Law in America: Volume III*, ed. Michael Grossberg and Christopher Tomlins (New York: Cambridge University Press, 2008), 238-239; Paul Starr, *Remedy and Reaction: The Peculiar American Struggle Over Health Care Reform, Revised Edition* (New Haven: Yale University Press, 2013), 36; Paul Starr, *The Social Transformation of American Medicine: The Rise of a Sovereign Profession & the Making of a Vast Industry*. (New York: Basic Books, 2017), 18-19, 58-59,112, 123-124.

[108] Philip King Brown, M.D., "Organized Medicine's Interest in a Health Insurance Plan for Small Wage Earners," *New England Journal of Medicine* Vo1. 205 No. 27, December 31, 1931, 1286; Russel VanArsdale Lee, M.D., "Pioneering in Prepaid Group Medicine," an oral history conducted by Gabrielle Morris, Earl Warren Oral History Project, Regional Oral History Project, Bancroft Library, University of California, 1971, 29-30; Starr, *Social Transformation*, 134-135, 142-144.

would inevitably always become more expensive as medical technology improved and patients came to expect better treatment.[109]

As important, another major change to the delivery of medical services occurred with the introduction of new methods by which individuals could pay for health care. The traditional fee-for-service model, which had patients paying for care based on specific treatments provided by the doctor, was challenged by prepayment group plans, which paid doctors on a monthly or annual basis for a certain amount of care. Fee-for-service was also challenged by the prospect of government-provided medical care. This chapter shows that despite the efforts of professional associations to defend fee-for-service, new models of private care began to expand to cover more individuals. These models remained limited to those who could pay for them through their own private resources, or obtain coverage through employment. While private coverage was expanding, those with lower incomes, or the unemployed—people like J.C. Smith—were pushed toward state-funded institutions such as county hospitals, and state departments for the disabled, notably the California Department of Education's Rehabilitation Services and the California Department of Public Health's Bureau of Crippled Children Services.[110]

The first part of this chapter traces the legislative empowerment of the private medical professional societies through statutes that gave them power to appoint members to the Board of Examiners that exercised legal authority to issue licenses to practice medicine in the state of California. I then show how this empowered medical profession, through its official body of the California Medical Association[111] (CMA), used litigation to quash competition from state entities such as county hospitals. County hospitals provided free care. Private physicians, with the support of the CMA, sued to limit care at county hospitals to those without the financial means to pay. Californians who could pay were to be forced to go to private providers. Only "indigent" Californians could be admitted to county hospitals, and among those the state courts defined as indigent were those with psychological impairments and minors with physical disabilities.

The CMA also restricted competition through state litigation that led to legal prohibition of for-profit group prepayment plans. The medical profession was considered to be a venerated profession requiring complete, undivided loyalty to the patient. The California judiciary ruled that for-profit corporate groups providing prepayment options were violating state statutes prohibiting the practice of medicine by a corporation that would divert the loyalty of physicians from patients to corporate shareholders. Overall, by 1940, litigation based on state constitutional provisions and statutes to limit competition and stem the tide of state intervention in healthcare enabled the CMA to dominate the structure of medical service delivery in California.

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[109] "Howard Hassard Obituary," *San Francisco Chronicle*, November 24, 1999, in H. Howard Hassard, "The California Medical Association, Medical Insurance, and the Law, 1935-1992," an oral history conducted in 1992, 1993 by Malca Chall, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1993,for Hassard's views on accessibility and cost of medicine, see 64-67; 93-94. Hassard even half-joked that the only way to keep costs down was euthanasia of the elderly.

[110] For analysis of separations between private and public health care coverage at the national level, see Jacob S. Hacker, *The Divided Welfare State: The Battle Over Public and Private Social Benefits in the United States* (New York: Cambridge University Press, 2002), 95, 103; Jennifer Klein, *For All These Rights: Business, Labor, and the Shaping of America's Public-Private Welfare State* (Princeton: Princeton University Press, 2003), 78-79; Jill Quadagno, *One Nation, Uninsured: Why the U.S. Has No National Health Insurance* (New York: Oxford University Press, 2005), 22-23.

[111] The California Medical Association has had many names over the years, and it was founded as the "California State Medical Society." For this paper, I use "California Medical Association" when referring to it and its predecessors.

The second part of the essay shows how Henry Kaiser and Sidney Garfield created a group prepayment system that would successfully compete for patients with the CMA and physicians providing care through fee-for-service payment methods. Garfield originally created a prepayment plan out of necessity when caring for workers at an aqueduct project in central California in the 1930s. His prepayment method grew as he was recruited to provide care for more and more workers on bigger and bigger projects, culminating in a prepayment plan for workers at the Kaiser shipyards in Richmond during World War II. The success of this endeavor ensured that it would not go unnoticed nor unchallenged by the established profession of physicians. It took another case before the California State Supreme Court to secure the legal legitimacy of Kaiser Permanente's prepayment model.

The dynamics of the Garfield-Kaiser challenge to fee-for-service demonstrate how state law had been used by the medical profession to hinder competition. But despite the expansion of coverage brought about by prepayment plans like Kaiser Permanente, coverage still did not extend to those without employment, which often included those considered disabled. Like fee-for-service, prepayment excluded the impoverished and those considered disabled from private care. Thus, corporate medicine joined the medical profession and the state courts in effecting the continued isolation of those coping with the effects of severe and disabling medical conditions in the underfunded and under-resourced state health care system. Ultimately, California law at both the legislative and judicial levels actively assisted in the creation of a two-tiered health care system that benefited private practitioners, whether solo or corporate. Doctors like Juliet Thorner and her patients at public institutions like Kern County General Hospital were lost in the shuffle.

I. The CMA Creates a Two-Tiered Health Care System Through State Law

This first section shows how, under the influence of the medical profession, the California state legislature created a licensing system that prohibited certain treatments and services from being categorized as the practice of medicine. Meant to legitimize the profession and protect patients, this licensing system also worked to create a limited class of medical professionals protected from competition. In the 1930s, this legally established process of delegating state licensing authority to the medical profession would be used to challenge efforts to expand health care coverage and decrease costs of medical care. In particular, the CMA would use litigation based on both statutes and constitutional provisions to mitigate the threat of competition from both the state and from group prepayment plans. This litigation created a two-tiered health care system in California: those who could pay were legally required to seek care from private medical providers, while those who did not have the financial means to pay for private care were forced into public state and county facilities.

A. Legislative Empowerment of Professional Medical Societies

The CMA was established in Sacramento on March 12, 1856, by seventy-six members of the medical profession from sixteen counties across Central and Northern California. It was created to solidify the professional practice of medicine and protect it against those whom physicians considered to be fraudsters and hucksters encroaching on their medical expertise. It was meant to set standards and discourage practices such as advertising and soliciting, which the CMA and its members considered immoral.[112] Necessarily, their noble intention of ensuring a

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[112] California Medical Association, "California Welcomes the American Medical Association in its Seventy-Fourth Annual Convention at San Francisco, June 25-29, 1923," Call # 644034_152, Los Angeles County Medical

high standard of care by licensed physicians and specialists also had the effect of limiting the number of people who could engage in the "practice of medicine" in the state of California.

In 1876, the state legislature approved an act that would regulate the practice of medicine. The act required those engaged in the practice of medicine to present the requisite qualifications and diploma to the state's Board of Examiners. The state's Examiners were to be recruited from State Medical Societies—including the CMA. The Board would "issue certificates to all who furnish satisfactory proof of having received diplomas or licenses from legally chartered medical institutions in good standing." The Act also defined "physician" as follows: "Any person shall be regarded as practicing medicine, within the meaning of this Act, who shall profess publicly to be a physician and to prescribe for the sick, or who shall append to his name the letters of 'M.D.'" Therefore, a board consisting of physicians from specific medical institutions and recruited from state medical societies would assess the credentials of prospective medical practitioners in order for applicants to be granted the legal right to practice medicine in the State of California. Those whom the board approved could hold themselves out to be "physicians" and use the abbreviation for "medical doctor." Anyone who violated the Act by representing themselves as physicians and/or practicing medicine without approval by the board would be subject to fines and jail time.[113]

Holding practitioners of medicine to account was not intrinsically problematic, nor would it necessarily have a deleterious impact on the general welfare of the people of California. On the contrary, accreditation protected individuals from harmful treatment by those who were not competent to practice. However, the legislature's delegation of authority to state medical societies filled its board of accreditation with practitioners whose credentialling processes necessarily limited the number of people who could practice medicine. More importantly, it granted professional medical societies legal authority to gatekeep the practice of medicine in the state.

In 1901, the state legislature further specified the composition of the medical licensing board by stating explicitly which medical societies would appoint board members, and how many members each society would be assigned. The legislature gave the CMA the largest number of seats—five. The California State Homeopathic Medical Society and the Eclectic Medical Society were each to select two. Thus, the CMA's appointees had the majority and could outvote members from the other two societies. The 1901 Act required that applicants aspiring to practice medicine show a diploma from a legally chartered medical school and pass a written test created by the Board of Examiners. Practicing without this credential would result in a fine or even jail time.[114]

Association Printed Materials Collection, Box 7, in The Huntington Library, San Marino, California, 52; Henry Gibbons, M.D., "Address to the California State Medical Society by H. Gibbons, M.D. at the Expiration of his Term of Office as President, 1872," in UCSF Library: Archives and Special Collections, Henry Gibbons Papers, MSS 73-5; Henry Gibbons, M.D., "Annual Address before the San Francisco Medical Society," November 9, 1869, in UCSF Library: Archives and Special Collections, Henry Gibbons Papers, MSS 73-5; Henry Gibbons, M.D., "University of the Pacific: Fifth Annual Announcement of the Medical Department, Session of 1862-1863, Valedictory Address delivered at the public commencement, held March 15, 1862," in UCSF Library: Archives and Special Collections, Henry Gibbons Papers, MSS 73-5; Henry Harris, *California's Medical Story* (San Francisco: The Grabhorn Press, 1932), 152.

[113] Chapter 518, "An Act to regulate the practice of medicine in the State of California," in *The Statutes of California Passed at the Twenty-First Session of the Legislature, 1875-6* (Sacramento: State Printing Office, 1876), 792-794, quotes on pages 792 and 794, respectively; Harris, *California's Medical Story*, 155-156.

[114] Chapter 51, "An act for the regulation of medicine and surgery in the State of California, and for the appointment of a board of medical examiners in the matter of said regulation," in *The Statutes of California and Amendments to*

Having granted the professional societies of California complete authority over the selection of members to this Board of Examiners in both the original 1876 Act and then again in the 1901 Act, the state legislature then chose to rescind that authority in March 1907, by passing an act instead delegating authority over the appointment of the Board of Examiners to the governor of California. Almost inevitably, however, the appointments made by the governor's office would be drawn from lists presented to it by the various medical societies of California. Foremost among these societies was the CMA, which would provide a list of ten names, of which the governor would select five. Other societies, such as the California State Homeopathic Medical Society, were to provide four names, of which two were selected.[115] Thus, although the legislature had shifted formal authority back to a state representative, the professional societies, and especially the leading medical society, retained exclusive power over who would fill this state entity with examiners, subject only to the governor's final selection from among the societies' nominees.

The new statute also revised the accreditation process, creating a three-tiered system: a certificate for the holder to practice medicine and surgery; a certificate for the holder to practice osteopathy; and a certificate for the holder to practice other methods not mentioned in the act. In order to procure a certificate, applicants needed diplomas from a medical school, college of osteopathy, or academic institution related to the alternative form of treatment, respectively. Proof of diplomas, a written examination, and penalties for illegal practice such as fines and jail time were all still in effect.[116]

In 1909, the state legislature amended the 1907 Act to clarify that those who had procured licenses prior to the 1907 Act were grandfathered into their respective practices, whether medicine and surgery, osteopathy, or other methods of treatment.[117] In 1911, the state legislature added a longer and more specific list of what constituted the fraud of practice without a license, emphasizing in particular the illegality of acquiring fraudulent diplomas and practicing under an assumed name and degree.[118]

This statutory history shows how the state legislature created a licensing process in California that both established a standard of care *and* limited access to the profession of medicine. In doing so, the state legislature constructed a professional class that would be able to select its own new members and set limits to entry. Increasing demand for medical care in the

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the Codes Passed at the Thirty-Fourth Session of the Legislature, 1901 (Sacramento: A.J. Johnston, Superintendent State Printing, 1901), 56-64.

[115] Chapter 212, "An act for the regulation of the practice of medicine and surgery, osteopathy, and other systems or modes of treating the sick or afflicted, in the State of California, and for the appointment of a board of medical examiners in the matter of said regulation," in *The Statutes of California and Amendments to the Codes Passed at the Thirty-Seventh Session of the Legislature, 1907* (Sacramento: W.W. Shannon, Superintendent, State Printing, 1907), 252-259.

[116] Chapter 212, *Thirty-Seventh Session of the Legislature*, 253-254, 257.

[117] Chapter 276, "An act to amend section sixteen of an act entitled "An act for the regulation of practice of medicine and surgery, osteopathy, and other systems or modes of treating the sick or afflicted, in the State of California, and for the appointment of a board of medical examiners in the matter of said regulation," in *The Statutes of California and Amendments to the Codes Passed at the Thirty-Eighth Session of the Legislature*, *1909* (San Francisco: Bancroft-Whitney Company, 1909), 418-419.

[118] Chapter 740, "An act to amend an act entitled, 'An act for the regulation of the practice of medicine and surgery, osteopathy, and other systems or modes of treating the sick and afflicted, in the State of California, and for the appointment of a board of medical examiners in the matter of said regulation,'" in *The Statutes of California and Amendments to the Codes Passed at the Thirty-Ninth Session of the Legislature, 1911* (San Francisco: Bancroft-Whitney Company, 1911), 1437-1441.

late nineteenth and early twentieth century thus met a decrease in the supply of those offering care, directly as a result of state legislation.

These statutes and amendments passed between 1876 and 1911 culminated into the California Medical Practice Act. The act composited and formalized the piecemeal measures of previous years, ensuring the medical profession would have all the legal tools it desired to limit the number of practitioners through control of the accreditation process. By the 1930s, the result was a very strong medical professional society that would use the statutes not just to maintain its monopoly of accreditation but also to attack alternative forms of service delivery developed under the state and corporate models. The CMA used litigation at the state level to funnel paying patients to private providers and non-paying patients to public providers, especially county hospitals; it also sought to limit the expansion of affordable payment models based on corporate structuring that challenged traditional solo practice and fee-for-service. In doing so, the CMA prevented competition from the state and limited competition from other more affordable private care providers.

B. Constitutional Restrictions on State Competition

The economic turmoil of the 1930s and the emergence of state interventions in what had been the private sector's domain did not spare the medical field. Before that tumultuous decade, those who could not afford to pay were cared for (when at all) by philanthropic physicians who donated their time and services. Prior to the intervention at the federal level through the Social Security Act, and later its amendments creating Medicare and Medicaid, the state welfare system would contact doctors to make house calls for Californians in need of care but unable to pay. In fact, the practitioners in question were often not yet accredited but were often medical students who were not paid for their services but gained experience, thereby subjecting those with lower incomes or no incomes to care by inexperienced students. For established clinics, such patients were known as "no charge" patients.[119]

One of the major sources of experienced care for Californians of all income levels was the county hospital. In the second half of the nineteenth century, public hospitals were an important institution for the care of single men who often had travelled to the state without family or a community to care for them. Forty-nine new county facilities appeared between 1874 and 1930, raising the number throughout the state from twenty-four to seventy-three.[120] Prior to 1936, individuals could seek medical care in tax-funded county hospitals without having to pay, regardless of their financial status. Patients might make a donation for their time and treatment at the hospital, but donations were not required to obtain care. This public option encroached on the business of private practitioners of medicine, and so in the case of *Goodall v. Brite* the CMA marshaled provisions of the California state constitution to limit public access to health care.[121] Arising in the heart of the Tulare Basin in California's San Joaquin Valley, *Goodall* furnished vital legal tools to force paying clients into private care and non-paying clients into public care.

Kern County's hospital was one of the public institutions that provided care for those who had the means to pay; it was the same hospital where Juliet Thorner would later treat J.C.

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[119] Henry Gibbons, M.D., "Annual Address before the San Francisco Medical Society," November 9, 1869, in UCSF Library: Archives and Special Collections, Henry Gibbons Papers, MSS 73-5; Lee, "Pioneering in Prepaid Group Medicine," oral history, Bancroft Library, 27-28; Howard Hassard, "Fifty Years in Law and Medicine: Reminisces," an oral history, (Howard, Bonnington, Rogers, and Huber, 1985), 21.

[120] Peter Newbanks Grant, "The Struggle for Control of California's Health Care Marketplace," Dissertation, Harvard University, May 25, 1988, 67-68; Harris, *California's Medical Story*, 110.

[121] *Goodall v. Brite*, 11 Cal. App. 2d 540 (1936); Brown, "Organized Medicine's Interest," 1288.

Smith. At the discretion of the hospital's board of supervisors, patients who had the means themselves, or who had relatives with means, were admitted for care in the county hospital. Private physicians saw this as the state stealing patients away from their businesses, so they engaged in litigation at the state level that would have the effect of granting them a monopoly of paying patients while channeling all nonpaying patients toward public institutions. *Goodall v. Brite* was a suit filed by Kern County physicians against the county hospital on behalf of the county's taxpayers. It sought to enjoin the institution from treating those who were able to pay for care, so-called "non-indigent patients." The suit did not oppose the treatment of those unable to pay, but if patients had the means to pay for care, Kern County physicians argued that those patients should be cared for by private medical providers. As the court would stress, care by the public county hospital was not due to an absence of availability at private facilities; private providers had the capacity to treat those patients who were seeking care from the public institution.[122]

The defendants argued that it was within the police power of the board of supervisors for the hospital, as a county institution, to operate using its discretion to select those for whom it would care and how it would care for them. They claimed that the health and general welfare of all county residents were well within the board's purview, and that their admission into the hospital's care of individuals without regard for their ability to pay or not pay was in keeping with the board's authority.[123] This argument from the defendant directly controverted the plaintiff's proposition that the admission of persons able to pay into care at tax-payer funded county hospitals violated Article IV, Section 31 of the California State Constitution, which prohibited the legislature from allocating public money or resources in the form of a gift.[124] The issue therefore was whether the county hospital's openness to treatment of all citizens, regardless of their capacity to pay, was within the board of supervisors' authority, or a violation of the State Constitution's provision prohibiting the use of public money as a gift. In other words, was the county's treatment of patients with means to pay a legitimate promotion of the general health and welfare, or was it a gift bestowed on private individuals by a state institution?

This question placed competing state constitutional provisions against each other: Article IV, Section 31 prohibited public gifts from the legislature; Article XI Section 11 bestowed police powers on localities, including counties. The dispositive factor in this case was the availability of private treatment options. The Court of Appeal for the Fourth Appellate District in California stressed throughout its opinion that because private health care options were available, the admission of patients to a county hospital enabled those individuals to retain their private resources rather than use them to obtain necessary care obtainable elsewhere.[125] It reasoned that patients with the means to pay who selected the public county hospital were not choosing between receiving care or not receiving care, they were choosing whether or not to spend resources on care. The case was therefore a question of private resource allocation rather than a question of public welfare. Once so understood, the court ruled for the plaintiffs: free treatment at county hospitals when the patients or their family could otherwise pay was an unconstitutional public gift. It enjoined county hospitals from admitting patients with means to pay for care.[126]

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[122] *Goodall v. Brite*, 540, 542-43.
[123] *Goodall v. Brite*, 543-44.
[124] *Goodall v. Brite*, 546.
[125] *Goodall v. Brite*, 543, 547.
[126] *Goodall v. Brite*, 547-48.

The court's decision in *Goodall* straddled and defined a line distinguishing health care as a commodity and health care as a public utility properly provided under state and county police powers. Counties were permitted to operate hospitals for those without the means to pay, thereby providing their residents with a form of public medical care. Private providers were able to stave off the encroaching threat of state-provided care while simultaneously shifting the responsibility of care for those unable to pay away from their facilities and to public facilities.

The court also contributed to the segregation of paying and nonpaying patients into a two-tiered system. Paying patients were prohibited from being admitted to county hospitals, which plugged a funding supply in the form of voluntary donations after stays. Along with taxation, such donations supplied the funds required for the operation of county hospitals. One criticism leveled at the practice of treating patients with means to pay was that it was a misallocation of taxpayer resources, and a siphon for grifters who wanted to save money at the taxpayer expense.[127] Indeed, some may have received care without donating, but county hospitals in Santa Barbara and Santa Maria received donations of as much as $40,000 and $20,000 respectively from patients who paid for services provided. So patients with means were contributing to funding the county hospitals through care in amounts far beyond their taxe. The coordinated effort of private physicians and state and county medical associations put a stop to the practice by requiring patients with the financial capacity to pay to use private hospitals and providers.[128] The loss of paying patients meant public county hospitals lost funding even as they became wholly responsible for those unable to pay.

County hospital supervisors did not accept this decision lightly. In fact their response was bellicose—one supervisor at San Joaquin General Hospital vowed to continue care for patients even if it meant going to jail.[129] But their options were very limited, for a crucial component of the decision was its deliberation over constitutional provisions. By making the admission by county hospitals of patients with means to pay turn on a constitutional provision wherever there were private options available, the court drastically reduced the legal possibilities available to defendants and their sympathizers. They had only two paths, both extremely challenging: an appeal to the State Supreme Court or a constitutional amendment through a plebiscitary referendum. Both would fail.

The first and immediate response was the appeal to the State Supreme Court. Eleven counties joined the Kern County Hospital's board of supervisors in its appeal to permit county hospitals to care for all patients, rather than the indigent alone. In their amici curiae, these counties claimed that their provision of care for all taxpayers was equivalent to providing all taxpayers other social services such as a police force, firefighters, and public schools, regardless of taxpayer means.[130] This framing placed the health care provided by the county hospitals within the legitimate purview of the county through its police powers, where local counties were exercising legitimate authority over the safety and welfare of their residents. But the State Supreme Court refused to hear the appeal, rendering the appellate court decision final and limiting proponents of care for patients with means to a constitutional amendment.[131]

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[127] "Court Halts Misuses of Hospital Aid," *The San Francisco Examiner*, March 31, 1936, 3.

[128] "County Cannot Take Hospital Pay-Patients," *The Santa Maria Daily Times*, February 3, 1936, 1, 4; "Indigents Only Eligible Cases For Hospitals," *The Lompoc Record*, February 7, 1936, 1, 5.

[129] "Hospital System to be Continued," *Stockton Daily Evening Record*, February 10, 1936, 13.

[130] "Hospital Aid Plea Backed," *The Los Angeles Times*, March 10, 1936, 12

[131] "Court Halts Misuses of Hospital Aid," *The San Francisco Examiner*, March 31, 1936, 3; "Decision Closes County Hospitals to Pay Patients," *The Fresno Bee*, March 31, 1936, 13 (3-B); "Pay Patients Barred From Co. Hospitals," *Santa Rosa Republican*, March 31, 1936, 3; "Ruling Shuts Hospitals to Non-Indigents," *The Sacramento*

Proponents of county hospital care for the "non-indigent" duly turned to mustering support for a constitutional amendment. Just one week after the decision by the Fourth Appellate District Court of Appeal, county hospital supervisors in San Joaquin and Kern Counties, along with other interested parties, began organizing a ballot initiative to put before the voters in November (1936).[132] Their effort picked up steam after the State Supreme Court declined to hear Kern County's appeal of the *Goodall* decision. The Attorney General, Ulysses S. Webb, provided the following description for the amendment: "Establishment and maintenance of hospitals for pay patients by political subdivisions. The initiative constitutional amendment authorizes the governing body of any city, county, or city and county to establish and maintain a hospital for the care and treatment of any resident thereof whether an indigent or non-indigent, and to enact rules prescribing the rates to be charged each resident, other than indigents, for hospital services and supplies."[133] The amendment ultimately failed to qualify for the ballot. The effort to implement a constitutional amendment through a plebiscitary vote nevertheless indicates the magnitude of the court's decision and of the obstacles it had placed to providing non-private care through county hospitals for people that did not qualify as "indigent."[134] By granting private medical practice a monopoly of patients with resources to pay for care, *Goodall* had comprehensively wrecked the county hospitals' funding model.

Goodall v. Brite showed private practitioners how to split the patient pool into those who could pay and those who could not pay. Those who could pay were funneled into private care, those who could not were funneled into county hospitals. But the case went even further by explicitly outlining who was "indigent" and therefore under the care of public, taxpayer funded county hospitals. *Goodall* did not just split the patient pool by means and resources, it also specifically listed the attributes of those who were to be considered "indigent" and therefore qualified for admittance to county hospitals. These groups included: the sick and dependent; those sick and partially dependent in need of emergency services; psychopaths and drug addicts; physically "defective" and "handicapped" persons under the age of eighteen, whose parents could not pay for care; those with tuberculosis (if they could pay for their tuberculosis treatment, they were required to do so); those who had to be quarantined due to a contagious disease; prisoners in need of hospitalization; county employees injured in the course of employment; and persons in need of immediate emergency services.[135] The services of county hospitals were limited to these groups. Anyone else was required to pay for private care.

Going beyond sickness, accident, and emergency, the *Goodall* list specifically included those under the age of eighteen who were considered physically "defective" and "handicapped" with parents who did not have the means to pay for care. The court thus tied treatment of the physical and likely permanent condition of disability, as a legal concept, to age and resources: physical condition, age, and the resources available to the parents of the individual were all

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Bee, March 31, 1936, 9; "Supreme Court Shuts Hospital to Pay Patients," *Stockton Daily Evening Record*, March 31, 1936, 1.

[132] "Supervisors of Two Counties Plan Initiative," *Stockton Daily Evening Record*, February 8, 1936, 1, 2.

[133] "Hospitals Seek Change in Law for Pay Patients," *The Fresno Bee*, April 5, 1936, 20; "Hospital Act is Backed by Farmers," *The Hanford Sentinel*, May 2, 1936, 1.

[134] "Initiatives by Title and Summary Year (1912-1922), at California Secretary of State website, *History of California Initiatives*, https://www.sos.ca.gov/elections/ballot-measures/resources-and-historical-information/history-california-initiatives.

[135] *Goodall v. Brite*, 553; "Appeal Court Limits Free Medical Aid," *The San Francisco Examiner*, February 1, 1936, 5; "Appeal Court Rules Paying Patients Out," *Stockton Independent*, February 2, 1936, 1; "Court Curbs Hospital Aid," *Los Angeles Times*, February 2, 1936, 29 (Part II, Page 15).

considered when arriving at a legal determination of disability in California. This had implications going forward deeper into the mid-twentieth century. Specifically, when young people considered disabled would come of age and seek access to equal social, economic, and political opportunities, they would find themselves facing off against state institutions in large part because their care by those state institutions had been mandated by law. Private practitioners had successfully washed their hands of responsibility for those considered disabled by siphoning them off into state care as "indigent" patients, who included children considered disabled, into state care. Patients like J.C. Smith.

Goodall's demarcation line for patients based on resources and capacity was precisely the outcome the CMA desired. During the case, Hartley Peart, the General Counsel for the CMA, acted as counsel for plaintiff physicians seeking to enjoin county hospitals from admitting those able to pay.[136] Once decided, the CMA also commended the outcome through its periodical, *California and Western Medicine*. It applauded the "courage" of the members of Kern County's medical association for bringing the case. It emphasized its solidarity and support for local medical associations in opposing public hospitalization of those patients who are able to pay for care.[137] The CMA used the decision to lobby the California state legislature on the capacity of the boards of supervisors of county hospitals to obtain a statute that would authorize county hospitals to admit patients who could pay. Both the boards of supervisors for county hospitals, as well as the state legislature, were *constitutionally* prohibited from allowing the admission of patients with means to pay at county hospitals.[138] Statutory and constitutional permissions clashed here, illustrating the additional power and force of a ruling based on a constitutional provision. Had this been a statute-based decision, proponents of non-indigent care at county hospitals could have pursued statutory remedies at the state legislature. The constitutional grounding precluded that option.

Two important legal developments in *Goodall v. Brite* relate to health care in California. First, the decision created a two-tiered system based on resources. Those who were able to pay were now forced to go to private practitioners, while those who were unable to pay could still be admitted to county hospitals. This economic distinction would funnel money and other resources to private practitioners and away from county hospitals and state facilities. Second, it defined "indigent" patients who could be admitted at county hospitals to include young people who were considered disabled. The decision created a legal schism in California health care—private practitioners caring for the able bodied and well resourced, and publicly-funded county hospitals relying on less funding and donated time by physicians and medical students caring for those considered disabled and with fewer resources.

C. Statutory Restrictions on Private Competition

If *Goodall* were not enough, the 1930s would also see another blow to affordable care for all Californians—the legal prohibition of private corporations from offering care at lower cost through prepayment plans. This 1938 case, *People ex re. State Board of Medical Examiners v.*

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[136] "Appeal Court Limits Free Medical Aid," *The San Francisco Examiner*, February 1, 1936, 5; "Kern County Hospital Case Decided," *California and Western Medicine* Vol. 44 No. 4 (1936), 253.

[137] "Kern County Hospital Suit: Appellate Court Enjoins Supervisors from Admitting Non-indigent Patients," *California and Western Medicine* Vol. 44 No. 3 (1936). 146-147; "Kern County Hospital Case Decided," *CWM* 253.

[138] "Kern County Hospital Case Decided," *CWM* 253; journalists at the *Hanford Morning Journal* reached a similar conclusion, see, "'Pay Patient' Scheme is Ruled Out by Court," *Hanford Morning Journal*, February 2, 1936, 6.

Pacific Health Corp.,[139] was brought by the state Attorney General Ulysses Webb. CMA lawyers Hartley F. Peart and Howard Hassard contributed as Amici Curiae on behalf of the state.[140] The suit claimed that Pacific Health Corporation (PHC) was engaged in the illegal activity of practicing medicine as a corporation, in violation of the California Medical Practice Act. It featured private practitioners (the CMA and its lawyers) and the state (the Attorney General) working in concert to suppress alternative forms of low-cost care for Californians that challenged the CMA's fee-for-service model.

Arguments for each side in *Pacific Health* focused on defining "the practice of medicine." Pacific Health Corporation defended its activity in two ways, one based on technical corporate structure, the other on the shifting social demands of health care. In its first defense, PHC argued that the physicians associated with the corporation were independent contractors that PHC simply supplied with medical tools and services, while also aiding in connecting them with patients.[141] The physicians were compensated by fees for services provided, rather than by salary. The attorney for the defendant and appellant, PHC, conceded that the corporate practice of medicine was illegal, but argued that PHC was not engaged in the corporate practice of medicine; PHC simply facilitated payments to physicians for care.[142] The California Supreme Court rejected this defense, ruling that the method of compensation did not avoid the divided loyalty problem. Whether their compensation was fee- or salary-based, the physicians' loyalty was divided between the patient and the corporation.[143]

In its second defense, PHC argued that an adverse ruling would send deleterious ripple effects throughout the health care industry by disrupting new but established methods of providing care. The defendants argued that a ruling against PHC would prohibit operations of other organizations that facilitated the practice medicine, such as fraternal orders and charities.[144] The California Supreme Court rejected this defense as well, ruling that such a shift in social policy must come from the legislature, and not corporations gone rogue.[145]

For his part, Attorney General Webb emphasized the issue of "divided loyalty." Physicians could not be loyal to both their client and the corporation that paid them.[146] Much was made of the reverence bestowed on physicians throughout history. Webb contrasted the physician as healer with a for-profit corporation and used passages from the Bible to support the

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[139] *People ex re. State Board of Medical Examiners v. Pacific Health Corp.*, 12 Cal. 2d 156 (1938); *People ex re. State Board of Medical Examiners v. Pacific Health Corp.*, in California State Archives, Inventory of the Supreme Court of California Records, SF1-SF20398 (1895-1960), S. F. No. 15690.

[140] *People v. Pacific Health Corp.*, 12 Cal. 2d at 156.

[141] "Appellant's Opening Brief," *People ex re. State Board of Medical Examiners v. Pacific Health Corp.*, in California State Archives, Inventory of the Supreme Court of California Records, SF1-SF20398 (1895-1960), S. F. No. 15690, at 20-26; John H. Riordan, "Oral Argument on Behalf of Appellant," *People ex re. State Board of Medical Examiners v. Pacific Health Corp.*, in California State Archives, Inventory of the Supreme Court of California Records, SF1-SF20398 (1895-1960), S. F. No. 15690, at 5, 7-11, 23. *People v. Pacific Health Corp.*, 158; "Health Corporation Denied Rehearing," *Oakland Tribune*, September 30, 1938, 24.

[142] "Appellant's Opening Brief," California State Archives, S. F. No. 15690, 2-6, 11-14; Riordan, "Oral Argument on Behalf of Appellant," California State Archives, S. F. No. 15690, 4-8, 15-16, 24-25.

[143] *People v. Pacific Health Corp.*, 158-159.

[144] "Appellant's Opening Brief," California State Archives, S. F. No. 15690, 44-46; Riordan, "Oral Argument on Behalf of Appellant," California State Archives, S. F. No. 15690, 29-30.

[145] *People v. Pacific Health Corp.*, 159-161; "Social Medicine Plan is Hit Blow," *The Modesto Bee*, September 3, 1938, 1, 4.

[146] U.S. Webb and Lionel Browne, "Respondent's Brief," *People ex re. State Board of Medical Examiners v. Pacific Health Corp.*, in California State Archives, Inventory of the Supreme Court of California Records, SF1-SF20398 (1895-1960), S. F. No. 15690, 10-18, 26-28.

former's elevated status.[147] He argued that precedent prohibited the engagement of middlemen in facilitating medical treatment or services for profit.[148] The importance placed on the "for profit" aspects of this intervention would be crucial in later attempts to develop group prepayment systems. By focusing heavily on PHC's incorporation as a commercial corporation with shareholders, prepayment plans would later incorporate as nonprofits under different statutory provisions in order to avoid association with profit-seeking corporate shareholders.

As had been the concern of the CMA since its inception, the respondents stressed the medical profession's ongoing concern at the prospect of unlicensed individuals advertising services under the pretenses of providing medical treatment, taking patients away from licensed physicians. The law's prohibition of advertising allowed the medical profession to exclude nonphysicians, like PHC, from representing themselves as medical providers.[149]

Like the Attorney General, the CMA lawyers in their amicus curiae brief highlighted PHC's status as a for-profit corporation answering to shareholders on the one hand, and the special professional status of doctors, lawyers, and dentists on the other. Doctors, lawyers, and dentists were prohibited from working as or for any corporate entity in order to confirm that their undivided loyalty was to the patient or client, and not to a third party loyal to shareholders.[150] Unlike the Attorney General's brief, the CMA went further to argue that the exact method of payment for physicians through the corporate entity was irrelevant. Whether the physicians were paid as salaried employees or independent contractors did not matter; what mattered was the corporation's role as a third party paying medical professionals as labor costs for a for-profit entity. This was no mere procedural disposition dependent on semantics; the point of the prohibition of the corporate practice of medicine was to prevent divided loyalty from corrupting the practice of medicine.[151] The CMA lawyers also argued that the patient's choice was crucial, and that allowing for the corporate practice of medicine would lead to advertising.[152] Prior to the California Supreme Court decision, the CMA had applauded the lower Superior Court's decision, praising the conclusion reached that corporations with stockholders interfered with the sacred relationship between doctor and patient.[153]

Although Pacific Health Corporation was a private, for-profit entity, some newspapers labelled it as "socialized medicine." The move away from solo practitioners' fee-for-service plans toward any group plan by a private provider was considered to be a move away from free markets.[154] The case also raised concerns that patients would not be able to choose their

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[147] Webb and Browne, "Respondent's Brief," California State Archives, S. F. No. 15690, 58.

[148] Webb and Browne, "Respondent's Brief," California State Archives, S. F. No. 15690, 32.

[149] Webb and Browne, "Respondent's Brief," California State Archives, S. F. No. 15690, 55-57.

[150] Hartley Peart and Howard Hassard, "Brief of Amici Curiae in Support of Respondent," California State Archives, Inventory of the Supreme Court of California Records, SF1-SF20398 (1895-1960), S. F. No. 15690, 2-9, 31, 36-46. Hartley Peart and Howard Hassard, "Supplemental Brief of Amici Curiae in Support of Respondent," California State Archives, Inventory of the Supreme Court of California Records, SF1-SF20398 (1895-1960), S. F. No. 15690, 27.

[151] Peart and Hassard, "Brief of Amici Curiae," S. F. No. 15690, 24-25, 32; Peart and Hassard, "Supplemental Brief," S. F. No. 15690, 4-12.

[152] Peart and Hassard, "Brief of Amici Curiae," S. F. No. 15690, 26-27, 28, 33-34.

[153] "Corporations Cannot Practice Medicine in California," *California and Western Medicine* Vol. 43 No. 6 (1935), 460-61; "Corporations Cannot Practice Medicine in California," *California and Western Medicine* Vol. 44 No. 1 (1936), 36-39.

[154] "Group Medicine in Private Firms Hit Blow," *The Bakersfield Californian*, September 3, 1938, 1; "Court Outlaws Medical Service By Corporations," *The Fresno Bee*, September 3, 1938, 2; "Socialized Medicine Plan Ruled Illegal," *News Pilot* (San Pedro, CA), September 3, 1938, 2; "High Court Upholds S.F. Health Service,"

doctors—the PHC operated a closed panel system, meaning it had a list of doctors from which patients had to choose in order for their prepayment plan to apply. Limiting patients to a group of doctors based on their prepayment was seen as an encroachment on the fundamental relationship between patient and doctor.[155]

The Supreme Court sided with the Attorney General and the CMA, and it made a point of emphasizing that PHC was a for-profit corporation that solicited the public and advertised its services.[156] California state law had established through statute and judicial precedent that corporations could not practice certain professions, including law, medicine, and dentistry. These professions had been placed on a legal pedestal through the concept of "divided loyalty." Attorneys, doctors, and dentists were considered to be in professions that needed to have complete and unimpaired loyalty to the patient or client. If these professionals also served shareholders and corporate officers that loyalty would be split between corporate profits and patients.[157] Left unstated, such a distinction of course allowed these professions to increase profits through limited competition.

On the same day as *Pacific Health*, California Supreme Court decided in *Butterworth v. Boyd*[158] that the city of San Francisco was within its powers as a municipality to create a health care system for its employees that deducted funds from paychecks to cover the costs of care. This case can be distinguished from both *Goodall* and *Pacific Health Care*. Rather than focus on whether care at taxpayer funded county hospitals for patients with means to pay were state "gifts" to private individuals, or whether a private corporation could provide care based on monthly payments, the case was primarily concerned with the powers allocated to municipalities by Article XI, Section 8 of the California Constitution.[159] The State Supreme Court ruled that municipalities were within their constitutionally allocated power to provide medical services to their employees.[160] Although not nearly as wide-ranging as state county hospitals providing care for all members of the community or the spread of private corporations creating methods of prepayment for care, this case did open the door slightly to the creation of state-run health care.

State litigation in the second half of the 1930s, based on both statutes and constitutional provisions, shows how the CMA tried to restrict competition from state institutions and from corporate entities developing new models of care. In the late nineteenth and early twentieth centuries the California state legislature had passed a series of statutes that would provide private state medical societies with expansive oversight of the credentialing process for medical practitioners. The CMA had used that oversight to mold both medical practice and delivery of services to its liking. In *Goodall v. Brite* private physicians in Kern County had successfully restricted competition from the state in the form of county hospitals. The decision sent those with few resources and those considered disabled to state institutions, forcing those who could pay to use private practitioners and depriving the state institutions of private donations. In *Pacific Health Corporation*, the state and the CMA teamed up to forestall medical care from a group prepayment plan organized as a corporate commercial enterprise.

Oakland Tribune, September 3, 1938, 3; "Up and Down California," *The Santa Maria Daily Times*, September 7, 1938, 6; "Co-op. Health Service Wins Decision," *Stockton Daily Evening Record*, September 3, 1938, 4.

[155] "Court Outlaws Medical Plan," *The Los Angeles Times*, September 3, 1938, 10.

[156] *People v. Pacific Health Corp.*, 157-158.

[157] *People v. Pacific Health Corp.*, 158-160; "Socialized Medicine Edicts Rendered by State Court," *The Pomona Progress Bulletin*, September 3, 1938, 1.

[158] *Butterworth v. Boyd*, 12 Cal. 2d 140 (1938).

[159] *Butterworth v. Boyd*, 146-47.

[160] *Butterworth v. Boyd*, 148.

This first part has thus revealed the concerted effort by the medical profession to use the California legal system to siphon off paying patients from state facilities while keeping nonpaying patients in state care. The state and the medical profession worked in tandem to restrict competition from private prepayment plans. And yet, during the tumult of the Great Depression and the industrial boom of World War II, Dr. Sidney Garfield and Henry Kaiser would work together to create a prepayment plan that would challenge the CMA and private practitioners up and down the State of California. To this we now turn.

II. Kaiser Permanente, the California Judiciary, and the Legal Entrenchment of the Two-Tiered System

In 1938, Dr. Sidney Garfield was looking for physicians and surgeons to staff the new prepaid medical program that he had created at Grand Coulee Dam in Washington State. First he paid a visit to Seattle's Washington Medical School. No one was interested in joining him. Then he tried Portland. Same result. So he headed for Los Angeles, where he himself had trained in his early years. Still had no luck. Stubbornly, Garfield delved deeper into his roots in Iowa where he had gone to medical school. Finally he found a physician he could recruit to join him. But he still needed a surgeon.

Eventually Garfield was referred to a young surgeon recently graduated from Stanford. His name was Dr. Cecil Cutting. Garfield pitched his idea of a prepayment model for the workers at the dam. Cutting was not convinced—he would have to think on it. Cutting already had a job in San Francisco as the assistant to a leading industrial orthopedic surgeon and he had already rubbed shoulders with members of the Bohemian Club. He and his wife had an apartment overlooking the bay at the bottom of Coit Tower on Telegraph Hill. Cutting ended the conversation by saying he would think it over. He would call Garfield later.

The young surgeon sought out the advice of a former classmate and friend from Washington, who highly recommended Garfield's plan and indicated he would in fact follow him to Grand Coulee if Cutting went. Still not convinced, Cutting called Garfield and said that Garfield would need to talk to his former dean, Dr. Loren R. Yank Chandler, Dean of Stanford Medical School.

Cutting and Garfield went to see Chandler together. Garfield entered the office first. Cutting waited outside for a half an hour until Garfield walked out looking forlorn. "I guess it's all over," he said. Then Cutting went in to talk to his former dean. Chandler did not mince words: "This idea of pre-payment, it's not acceptable in medical ethics," said Chandler. "If you go up there you'll be ostracized for life. You won't get into medical society, you won't be admitted to hospitals. You can't do it." Rather than dissuading Cutting, however, Chandler's warning actually enticed him. It was a challenge. He talked it over with his wife and she encouraged him to fly up to Grand Coulee to check it out. It was a small hospital but Cutting liked the look of it. He told Garfield he would take the job.[161]

A. Kaiser Permanente Expands Coverage for the Employed

Cutting may not have realized it at the time, but he had been invited to join what would become an industry-altering experiment that would change health care in California and the

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[161] Cecil Cutting, "Cecil Cutting, MD" interview conducted by Martin Meeker in 2006, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2006, 3-4; Cecil C. Cutting, "History of the Kaiser Permanente Medical Care Program," an oral history conducted in 1985 by Malca Chall, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1986, 4-6.

United States. Prepayment plans for medical care existed in California before Kaiser Permanente,[162] but not nearly to the degree of its scope and scale. Starting in the 1860s, the Southern Pacific Railroad had created a prepayment plan through its Southern Pacific Hospital Association that provided medical care for its employees. French and German communities in San Francisco set up their own hospitals based on prepayment models.[163] But Kaiser and Garfield created an innovative prepayment model that was backed by a billionaire entrepreneur with the resources of an industrial empire based on vast World War II shipbuilding and construction projects. This well of resources could support Garfield and the other doctors in the face of strident opposition from the CMA and AMA as they sought to expand the prepayment model across the state and the nation.[164]

The Kaiser Permanente model began in 1933 with Dr. Sidney Garfield in the Southern California desert. There, Garfield developed a 12-bed hospital to provide care to workers constructing an aqueduct that would deliver water from the Colorado River to Los Angeles. He originally used a fee-for-service model but realized workers could not afford to pay, and so he switched to a prepayment model that charged ten cents a day per worker, with five cents from a payroll deduction and five cents from insurance carriers.[165] This cost-saving measure provided Garfield with a guaranteed, secure income and provided the workers with medical care. The two major components of the model were prepayment funding and closed-panel physician selection. Prepayment funding meant that patients were charged on a monthly basis for a certain number of services. Closed-panel selection meant patients could only receive treatment from the physicians employed by the provider. Physician services beyond the plan provider would not be covered by the monthly payments.

Garfield was recruited by Henry Kaiser to implement the same model at the Grand Coulee Dam construction site in eastern Washington State. At first, he was reluctant. He wanted to settle down in Los Angeles after a taxing experience at the aqueduct. However, Kaiser's oldest

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[162] Like the California Medical Association, Kaiser Permanente had many names over the years and was often an amalgamation of different entities. For this paper I use "Kaiser Permanente" when referring to the Garfield-Kaiser prepayment model throughout its life cycle.

[163] Brown, "Organized Medicine's Interest," 1287; Paul de Kruif, *Kaiser Wakes the Doctors* (New York: Harcourt, Brace and Company, 1943), 37; Grant, "California's Health Care Marketplace," 51; Harris, *California's Medical Story*, 114-115; Lee, "Pioneering in Prepaid Group Medicine," 23-24; Peart and Hassard, "Supplemental Brief," 23-24.

[164] Hassard, "Fifty Years in Law and Medicine," 67-68.

[165] de Kruif, *Kaiser Wakes the Doctors*, 24-43; Scott Fleming, "Kaiser Permanente Medical Program History," published by Kaiser Foundation Health Plan, Inc., August 25, 1983 from Kaiser-Permanente Medical Care Program oral history records and related materials at the Bancroft Library, U.C. Berkeley, BANC MSS 91/12 c, Box 2; Sidney R. Garfield, "Historical Remarks," on April 24, 1974, from Kaiser-Permanente Medical Care Program oral history records and related materials at the Bancroft Library, U.C. Berkeley, BANC MSS 91/12 c, Box 2; Rickey Hendricks, *A Model for National Health Care: The History of Kaiser Permanente* (New Brunswick: Rutgers University Press, 1993), 19-27; Letter from Gordon Hendry to Robert C. Elliott, including a draft of an article by Henry Kaiser titled "We Do Not Need Socialized Medicine," no date, in the Henry J. Kaiser Papers at Bancroft Library, BANC MSS 83/42c, Carton 43; Raymond Kay interview by Norman Mondz, March 20, 1985, from Kaiser-Permanente Medical Care Program oral history records and related materials at the Bancroft Library, U.C. Berkeley, BANC MSS 91/12 c, Box 2; Raymond M. Kay, *Historical Review of the Southern California Permanente Group: Its Role in the Development of the Kaiser Permanente Medical Care Program in Southern California* (Los Angeles: Southern California Permanente Medical Group, 1979), 1-2; Raymond M. Kay, Presentation to the 1985 Regional Conference, "Kaiser Permanente Medical Care Program: Its Origin, Development, and Their Effects on its Future" from Kaiser-Permanente Medical Care Program oral history records and related materials at the Bancroft Library, U.C. Berkeley, BANC MSS 91/12 c, Box 2.

employee, Alonzo Ordway, asked Garfield to check out the dam as a favor to him, which Garfield felt obligated to do as Ordway had been instrumental in helping him set up the prepayment plan at the aqueduct. Even with this concession Garfield almost did not go; Edgar Kaiser (Henry's son) left him waiting outside his office for nearly two hours and Garfield had been just about to leave when Edgar Kaiser finally called him in. Still, they travelled up to Coulee Dam and once there Garfield saw that the project had the potential for an expansion of the prepayment model to cover far more workers. He committed to the project and applied the same prepayment model he used at the aqueduct in Southern California, with payroll deductions used to cover medical care. At Coulee Dam Garfield expanded his model from applying to the workers alone to include their families as well.[166]

After construction projects in Southern California and Eastern Washington, the Kaiser/Garfield prepayment model moved to Kaiser's shipyards in Richmond, California during the 1940s. The United States had entered World War II and workers from across the country descended on the shipyards. Kaiser again asked Garfield to implement and expand the prepayment model, this time to an even greater number of workers.[167]

Kaiser Permanente's prepayment model was met with firm opposition by the medical profession, both inside and outside the courtroom. Local, state, and national medical societies expelled and excluded doctors who joined Kaiser Permanente, branding them as "socialists" and "communists."[168] One of the reasons Garfield's early plans had been successful was that they had been established in relatively remote areas far from metropolitan centers, and importantly, outside the purview of medical societies. Both the Parker Dam aqueduct and the Grand Coulee Dam projects were far removed from cities such as Los Angeles and Seattle and their powerful medical communities which ostracized doctors who worked for prepayment plans. Further, World War II's mandates allowed for experimentation in war industry employee coverage at the same time as physicians who would normally have opposed its innovations were being drafted and sent abroad on military service. Innovation and a desire for extended coverage alone was not enough to sustain the development of an alternative to the fee-for-service model; it also required the existence of exogenous factors, like geographical isolation and an existential military threat.[169]

The development of Kaiser Permanente's prepayment model added a new and vital aspect to health care coverage expansion in California during the 1930s and 1940s—the

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[166] de Kruif, *Kaiser Wakes the Doctors*, 52-64; Fleming, "Kaiser Permanente Medical Program History," BANC MSS 91/12 c, Box 2; Kay, Presentation to the 1985 Regional Conference, BANC MSS 91/12 c, Box 2; Kay, *Historical Review*, 2; "Cecil Cutting, MD" interview, 1-2; Hendricks, *A Model for National Health Care*, 13, 29-36.

[167] "Cecil Cutting, MD" interview, 4-6; Fleming, "Kaiser Permanente Medical Program History," BANC MSS 91/12 c, Box 2.

[168] M.F. Colleen, "Historical Remarks," on April 24, 1974, from Kaiser-Permanente Medical Care Program oral history records and related materials at the Bancroft Library, U.C. Berkeley, BANC MSS 91/12 c, Box 2; "Cecil Cutting, MD" interview, 3, 6; Hendricks, *A Model for National Health Care*, 7-8, 10, 13-14, 39-40; Kay, Presentation to the 1985 Regional Conference, BANC MSS 91/12 c, Box 2; Lee, "Pioneering in Prepaid Group Medicine," 31-32; James Vohs interview conducted by Norman Mondz on January 24, 1985 in Kaiser-Permanente Medical Care Program oral history records and related materials at the Bancroft Library, U.C. Berkeley, BANC MSS 91/12 c, Box 2.

[169] de Kruif, *Kaiser Wakes the Doctors*, 40-41; Hendricks, *A Model for National Health Care*, 20. As Scott Fleming writes in his history of Kaiser Permanente, ""The special circumstances of isolated construction projects and the intense pressures of World War II provided both opportunities and stimulus for doing things differently and for taking direct and simple approaches." See, Fleming, "Kaiser Permanente Medical Program History," BANC MSS 91/12 c, Box 2.

employment imperative. The efforts of Henry Kaiser and Sidney Garfield certainly expanded health coverage to those who had gone without it. However, the health care they provided was absolutely contingent on employment. The prepayment model proved to be an effective method for providing more comprehensive health care to ever greater masses of workers and their families, but it was still a private enterprise meant to cover the employed.

Bouts of innovation occurred with discussions of "socialized" medicine always looming in the background. The CMA relentlessly accused Kaiser Permanente of engaging in socialized medicine, while Kaiser Permanente, and especially Henry Kaiser himself, consistently insisted that his health care organization was involved in no such thing. On the contrary, Kaiser argued that his prepayment, closed panel model was in fact a cost-effective alternative to "socialized medicine," saying, "I have always encouraged the extension of this type of plan [Kaiser Permanente] as a working answer to socialized medicine."[170] This argument over whether any new private group was engaged in some form of state-sponsored collectivized medical care was crucial because the insistence on *both* sides of the argument on private competition emphasized payment by private individual patients with their own private resources. The issue, stripped to essentials, was fee-for-service or prepayment. Both were private sector models for health care delivery. The private sector, with paying customers as patients, was where this competition was occurring. Public options and resources were eschewed and denigrated.

Still, debates over socialized medicine and role of government in providing care certainly raged in California, at both the federal and state level. During the 1930s the CMA had even considered a model of compulsory health insurance. During the 1940s Governor Earl Warren made multiple attempts at developing government-provided medical care at the state level. Opposition from private practitioners defeated both efforts.[171] So the specter of government-provided medical care loomed over the battle between medical associations defending the traditional fee-for-service model and Kaiser's group prepayment model.

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[170] For how Kaiser Permanente doctors were labelled as socialists and communists by the CMA and private doctors, see, James Vohs, interview, BANC MSS 91/12 c, Box 2; "Cecil Cutting, MD" interview, 6. For how Kaiser defended his prepayment plan as an alternative to socialized medicine, see, Letter from Gordon Hendry to Robert C. Elliott, BANC MSS 83/42c, Carton 43; "Henry Kaiser Defends his Health Plan: Agrees with CMA on Peril of Socialized Medicine," *San Francisco Examiner*, December 15, 1953 (quote here); "Highlight Points for Discussion with A.M.A.," no date, in the Henry J. Kaiser Papers at Bancroft Library, BANC MSS 83/42c, Carton 44; Kaiser editorial materials prepared for "LOOK" Magazine, "We Do Not Need Socialized Medicine" Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 43; "The Kaiser Permanente Medical-Care Plan: Remarks of Hon. James E. Murray of Montana in the Senate of the United States, Wednesday July 6, 1949," in the Henry J. Kaiser Papers at Bancroft Library, BANC MSS 83/42c, Carton 43.

[171] Lester Breslow, "Vision and Reality in State Health Care: Medi-Cal and Other Public Programs, 1946-1975," an oral history conducted 1984 by Gabrielle Morris, Regional History Office, The Bancroft Library, University of California, 1985, 33-35; John Mack Faragher, *California: An American History* (New Haven: Yale University Press, 2022), 359-360; Howard Hassard, *Fifty Years*, an oral history, 21-27, 41-47; Lee, "Pioneering in Prepaid Group Medicine," oral history, 22; Grant, "California's Health Care Marketplace," 3; Daniel J. B. Mitchell, "Impeding Earl Warren: California's Health Insurance Plan That Wasn't and What Might Have Been," *Journal of Health Politics, Policy and Law* 27 No. 6, (December 2002), 951-52, 955, 957-70; Starr, *Social Transformation*, 272, 282; Earl Warren, "Conversations with Earl Warren on California Government," an oral history conducted in 1971 and 1972, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1981, 152-154; Earl Warren, "My plan for health insurance," in The Bancroft Library, Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 77; Earl Warren, "Public Health," in *Public Papers*, 33-37; Earl Warren, *The Memoirs of Earl Warren* (Garden City, New York: Doubleday & Company, Inc., 1977), 177, 187-188.

B. Friction in Private Care: Kaiser Permanente and Medical Societies Clash

Physicians operating outside of Kaiser Permanente and other prepayment plans opposed the shift away from the traditional fee-for-service model and toward care based on regular payments. The conflict between these two private options—fee-for-service and prepayment—took two major forms. One was the expulsion and denial of membership of doctors employed by prepayment entities from state and county medical societies. The second was competition for large coverage contracts with labor unions.

Local county medical societies explicitly singled out Kaiser Permanente as a threat to their business. Prepayment plans were encroaching on solo practitioners' patient pool by undercutting prices. Medical professional societies felt this was an assault on their livelihood, and that they were being painted as "evil" by prepayment supporters. Although private prepayment systems were not government sponsored, medical society representatives framed those systems as an imposition on the "free and unfettered private practice of medicine." Efforts to counteract the rise of prepayment models included a plan from the CMA to create fee schedules aligned with local economic conditions and provide insurance to the patient for major costs of that care.[172] Private fee-for-service practitioners were responding to the rise of prepayment plans through lower costs for care and transparency of fee schedules, but care was still based on individual fees charged to individual patients.

The adversarial relationship between fee-for-service doctors and prepayment doctors was played out in membership inclusion and exclusion from professional medical societies. Kaiser Permanente outlined how different county medical societies were rejecting or ignoring applications from their doctors. A company memo noted that doctors were accepted only after leaving the prepayment group, and others were advised against applying while employed at Kaiser Permanente. The Alameda-Contra Costa Counties Medical Society, the San Francisco County Medical Society, the Solano County Medical Society, and the San Bernardino County Medical Society were all listed as professional societies that had excluded and rejected Kaiser Permanente doctors. "Whispering campaigns" warned doctors that if they were to join Kaiser Permanente they would not be accepted into medical societies, and they would be excluded from specialty boards relevant to their field.[173] Professional ostracism continued to plague doctors who sought to operate outside the traditional fee-for-service model.

When it came to Sydney Garfield himself, ostracism escalated to legal defenestration. Witness the case of *Garfield v. Board of Medical Examiners*.[174] In the late 1940s the Board of Medical Examiners ruled that Garfield had engaged in unprofessional conduct and it ordered that his license be suspended for one year. This suspension was downgraded and replaced with a five-year probation period during which Garfield would report to the Board at its regularly scheduled meetings in San Francisco.[175] Garfield then petitioned the superior court for a writ of mandate that would set aside the decision of the Board, and the trial court did so, entering judgment in favor of Garfield.[176] The Court of Appeal for the First Appellate District stated that the question before it was only evidentiary—had there been sufficient evidence to find that Garfield had

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[172] Paul D. Foster, "The Bulletin of The Los Angeles County Medical Association," by the President of the Los Angeles County Medical Association, March 5, 1953, in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78.

[173] "County Medical Societies' Refusal of Memberships to Doctors Serving Kaiser Foundation Health Plan Members," no author, no date, in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78.

[174] *Garfield v. Board of Medical Examiners*, 99 Cal. App. 2d 219 (1950); Hassard, "The California Medical Association," an oral history, 104.

[175] *Garfield v. Board of Medical Examiners*, 220-221.

[176] *Garfield v. Board of Medical Examiners*, 221.

engaged in unprofessional conduct? Specifically, the Board of Examiners had ruled that Garfield had employed physicians as interns at his hospital in violation of the Business and Professions Code. The court assessed whether there was substantial evidence that the doctors employed by Garfield were registered with the Board of Medical Examiners and engaged in work at the hospital as interns.[177] Ultimately the Appellate Court ruled that there was sufficient evidence for the Board to have found Garfield in violation of the Code and that he was appropriately sanctioned.[178]

From the perspective of the Kaiser Permanente organization and its sympathizers, this was hostile litigation begun in bad faith purely as a reaction to the success of the prepayment closed panel model in the 1940s.[179] Garfield and Kaiser took personal offense at the legal action, and it strained the relationship between the medical societies and Garfield in particular.[180] The consequences of the legal action were minor; intended as a slap on the wrist, it had no lasting impact on the operations of Kaiser Permanente or the work of Garfield. However, the case does represent the lengths to which private practitioners were willing to use the Board of Examiners to oppose the continued development of emerging prepayment closed panel models in the wake of World War II, and to punish their advocates.

Another arena of conflict between traditional fee-for-service medical care represented by state and county medical societies and private non-profit prepaid care represented by Kaiser Permanente was competition over union contracts. During the summer of 1953, Kaiser Permanente and local doctors competed for thousands of patients through a contract to provide care to the United Steelworkers Union, Local 1440 in Northern California. The steelworkers in Pittsburg, California voted decisively for health care through Kaiser Permanente over an alternative sponsored by local doctors.

The clash between Kaiser Permanente and the local doctors began with the construction and opening of a ninety-four-bed hospital in Walnut Creek that cost $1,500,000. Kaiser Permanente also planned to build a clinic in Pittsburg and submitted a plan to the steelworkers' union that covered all hospitalization costs. The local doctors responded with what was called an "unprecedented" prepayment plan by the local press.[181] Essential aspects of the Pittsburg doctors' plan were the lowering of prices for surgery and hospitalization in keeping with existing Blue Cross prices, coverage of pre-natal, delivery, and post-natal care, no captive patients tied to a particular doctor, and shared authority between three doctors and three representatives from the union overseeing the plan. Local private doctors were on the defense against what newspapers were literally calling an "invasion" by Kaiser Permanente.[182]

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[177] *Garfield v. Board of Medical Examiners*, 221.

[178] *Garfield v. Board of Medical Examiners*, 231.

[179] Scott Fleming, "History of the Kaiser Permanente Medical Care Program," an oral history conducted in 1990 and 1991 by Sally Smith Hughes, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1997, 21; Fleming, "Kaiser Permanente Medical Program History," BANC MSS 91/12 c, Box 2.

[180] Hassard, "The California Medical Association," an oral history, 109.

[181] Neil Dickson, "On Health Plan Front: Rivalry Perking, But Under Wraps," *Pittsburg Post-Dispatch*, week of July 13, 1953.

[182] "City Medics Ready Own Plan In Face Of Kaiser 'Invasion,'" *Pittsburg Post-Dispatch*, June 22, 1953 in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78; "Pittsburg Doctors Offer 'Prepaid' Medical Scheme," *Pittsburg Post-Dispatch*, June 23, 1953 in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78; "Traditionalism vs. Kaiser Plan: Medic Hits Union In Health Rumpus," *Pittsburgh Post-Dispatch*, July 20, 1953, in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78; "Doctors Wage Showdown Fight: Patients Have the Final Say!" Undated memo, no author, in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78, at 3.

A major criticism of Kaiser Permanente by the CMA was the closed panel system that forced patients to choose from a select group of physicians. Just as in *Pacific Health*, the CMA argued that Kaiser Permanente's closed panel system was a violation of medical ethics and an unfair deprivation of choice in the patients' selection of physician. This was the advantage that local doctors, and more broadly the CMA, both pressed against Kaiser Permanente. Edwin H. Logan Jr., a Pittsburg Community Hospital Administrator, warned against the encroaching closed-panel prepayment system, stating that if Kaiser Permanente established a foothold in the area, individuals would lose their ability to choose between doctors and might no longer have access to the community hospital. Logan went on to press the issue of patient choice, saying that patients could "…dictate your own policies to your own hospital but you could not do this under the Kaiser plan." Dr. Samuel L. Bernstein, a member of the board of Pittsburg Community Hospital, argued that Kaiser Permanente was destroying "the traditional relationship between the family doctor and the patient."[183] Dr. Paul D. Foster, president of the Los Angeles County Medical Association, argued against Kaiser's assertion that the free choice of physician was an "'outmoded concept,'" claiming that medical ethics and his training could not be reconciled with "a dictatorial, closed-panel plan that is diametrically opposed to the ideals that have allowed Medicine to progress and grow strong as a guardian of health and as a guardian of freedom for both the doctor and patient."[184] The veracity of all these claims is dubious. The professional hold on power and care already meant a patient's choice among doctors was limited, regardless of whether they were presented to the patient through closed panels or open choice. In other words, patients were always limited to the number of doctors in their area and the fee schedules those doctors imposed. Kaiser Permanente also offered limited choice, but at a lower cost. Local doctors offered a slightly expanded choice, but if their fees were prohibitively expensive, then their business model of "free choice" could keep those of lower income from receiving any medical care at all. Kaiser Permanente drew a clear line of demarcation between its doctors covered through their prepayment plan and doctors outside it, but Kaiser Permanente was constantly adding physicians and services to the pool of options available to patients. In areas where Kaiser Permanente opened facilities, patients in the area could now choose between its model and the existing care offered by physicians. If anything, Kaiser was expanding patients' choice, not limiting it.

Regardless of the strength of the arguments by doctors outside the Kaiser Permanente group, the ferocity and intensity of their arguments represented just how threatening the loss of the union workers to the newly constructed Walnut Creek Hospital and the clinic in Pittsburg was to the doctors. The insurance committee of the union accepted Kaiser Permanente's plan, but that was not binding on the membership, it was simply an advisory decision advocating that the union as a body select that option. The entire union membership would still have to vote for the Kaiser Permanente plan or the local doctors' plan through a plebiscitary vote.[185]

In September 1953, the Pittsburg steelworkers voted for the Kaiser Permanente plan, despite an in-person last-ditch effort by local doctors and their wives to solicit the business of the union by handing out fliers charging that union officials had misrepresented their plan. Local

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[183] For Logan's position, see "Local Doctors' Plan 'Far Exceeds' Kaiser's, Hospital Chief Declares," *Pittsburg Post-Dispatch*, July 14, 1953 in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78; for Bernstein's position, see "Traditionalism vs. Kaiser Plan," BANC MSS 83/42c, Carton 78.

[184] "Your President Says [Statement of the President of the Los Angeles County Medical Association]," *The Bulletin of the Los Angeles County Medical Association*, May 21, 1953, in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78.

[185] Dickson, *On Health Plan Front*, *supra* note 79.

doctors had even planned for a plane to fly over the steel plant and drop fliers if they had not been allowed to enter the facility.[186] That contingency plan was not needed, but it shows how far the local doctors were willing to go to oppose the Kaiser Permanente plan.

The final tally was a firm rejection of the local doctors—the steelworkers voted for Kaiser Permanente by a nearly five-to-one margin, with 2,182 votes for Kaiser Permanente and 440 votes for the local doctors' plan.[187] It was a clear rejection of the private practitioners despite their new and dramatic shift in offerings of care. Private practitioners who had spent years calling for patient choice in physician and the merits of competition as opposed to a state-sponsored alternative were now faced with the consequences of large groups of patients choosing different doctors and plans that were competing with their business.

In Southern California another fight would break out between Kaiser Permanente and the CMA over the business of a union. This time they competed for over 20,000 workers in the International Association of Machinists unit at Douglas Aircraft's Santa Monica Plant. The CMA ended up winning the contract, but it had to make steep concessions to keep the workers from choosing Kaiser Permanente. Physicians in the Santa Monica area agreed to waive salary ceilings, meaning that they would not charge more for workers earning more than an annual salary of $4,200. They also lowered their fees to be competitive with Kaiser Permanente's closed panel system and allowed for indemnity-type health insurance, where patients would be reimbursed by an insurance agency after paying their doctor. These new concessions were a result of the competition from the spreading Kaiser Permanente health plan.[188]

Though no doubt privately disappointed after losing out to the CMA's California Physicians Service (CPS) in Santa Monica, Henry Kaiser expressed confidence and optimism in the press. After the workers signed with CPS, Kaiser emphasized the role his organization was playing in reducing the costs of medicine for the patient through private competition, saying, "The actions of the doctors demonstrate that a victory for the people is in sight. It appears that some of the opposition to the Kaiser Foundation Health Plan has turned to recognition through a desire to compete with the services we are rendering to the people."[189] Kaiser might have been drawing attention to his own business and painting his organization in a flattering light, but he was correct in saying that competition from Kaiser Permanente was rattling the medical profession and forcing prices down in favor of the patients. When Dr. Bernard J. Korn of San Pedro was asked why the CPS was making concessions, he candidly stated, "I'll tell you why. Because the union was within a pen's scratch of signing with Kaiser."[190] The competition with

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[186] Neil Dickson, "Whoop-Te-Do Ends, Steelworkers Flock To Vote For Medical Scheme," *Pittsburg Post-Dispatch*, September 3, 1953 in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78.

[187] "Steelworkers Favor Kaiser By Thumping 5 To 1 Margin," *Pittsburg Post-Dispatch*, September 4, 1953, in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78.

[188] "Doctors to Widen Health Insurance: Physicians Negotiating With Union for Plan That Won't Penalize Higher-Income Workers," *Los Angeles Times*, December 14, 1953 in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78; Milton Silverman, "CMA Told Kaiser Has Lost At Douglas Plant," *The San Francisco Chronicle*, December 15, 1953 in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78.

[189] "Henry Kaiser Defends his Health Plan: Agrees with CMA on Peril of Socialized Medicine," *San Francisco Examiner*, December 15, 1953, in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78; "Kaiser Hails New Health Care Plan: Industrialist Lauds Doctors' Willingness to Drop Salary Ceilings in Contracts," *Los Angeles Times*, December 15, 1953 in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78; "Kaiser Hails the CMA 'Victory,'" *San Francisco Chronicle*, December 15, 1953 in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78.

[190] George Dusheck, "CPS in Southland Expands Coverage: Medical Societies Competing With Closed-Panel Service," *San Francisco News*, no date given, in Henry J. Kaiser Papers, BANC MSS 83/42c, Carton 78.

prepayment models offering closed panel systems was an existential threat to traditional fee-for-service models, and the CMA had been compelled to make major changes to its business model.

The struggles of local doctors, medical societies, and the CMA against the encroachment of prepayment closed-panel care from Kaiser Permanente show that no matter who won between the two private parties, there was one consistent winner—employed patients with resources. Unfortunately, patients like J.C. Smith, those who were without the ability to pay or obtain employment, were not included in the expansion of coverage. Moreover, in the wake of all the ostracism of Kaiser physicians and the clashes over union contracts, there still remained the issue of whether an entity like Kaiser Permanente could in fact operate as a conduit between physicians and patients. The CMA and its lawyers would argue that this was the unlawful practice of medicine, and both sides would draw on the *Pacific Health* precedent to make their case in the courtroom.

C. Legal Enshrinement of Prepayment Plans in California State Law

In 1954 the legal status of nonprofit prepayment as a means to coordinate medical care between patients and physicians was legally legitimized by the California State Supreme Court. The plaintiff, Complete Service Bureau (CSB), had filed a complaint alleging that the San Diego County Medical Society, along with the CMA, were engaged in a conspiracy in restraint of trade. The defendant medical societies cross-complained alleging that CSB was unlawfully engaged in the corporate practice of medicine, and engaged in fee splitting, solicitation, and commercialization of medical practice. The Court emphasized that the essential question at issue was “whether the activities of the cross-defendants constitute the unlawful practice of medicine as alleged in the cross-complaint.” [191]

This case was another opportunity for Kaiser Permanente and the private medical associations of California to spar with each other about the optimal implementation of medical care in California. The fundamental question was similar to that of *Pacific Health*, which was essentially what role entities could play in providing care. What did it mean for a corporate or nonprofit entity to be “practicing medicine?” Did it matter if the entity was organized as a commercial corporation or a nonprofit organization? Lawyers for the CMA and Kaiser Permanente would grapple with these questions in *Complete Service Bureau v. San Diego County Medical Society*.

The lawyers for Kaiser Permanente stressed the distinction between commercial corporations and nonprofit organizations in their amicus curiae brief. They conceded that no entity, no matter how organized, should interfere with the practice of medicine and the relationship between the physician and patient. They also conceded that solicitation should be prohibited. However, the brief emphasized that coordination of care for a group of individuals with an independent group of physicians by a nonprofit entity was legally permissible. They drew on the *Pacific Health* precedent by arguing that it allowed the public to join a prepaid plan as long as it was not operated for a profit and laypeople were not interfering with medical treatment by physicians. The Kaiser Permanente lawyers ended their brief with a call for affordable care to stave off the threat of state-sponsored “socialized” medicine, writing, “To strike down such health plans would not aid the medical profession, but only force adoption of a compulsory health plan by the federal or state governments. The people of this state want, and

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[191] *Complete Service Bureau v. San Diego County Medical Society*, 43 Cal. 2d 201, 204-205 (1954).

are entitled to, an opportunity to obtain low cost medical care."[192] Despite their efforts to provide low-cost care to more Californians, Kaiser Permanente stressed its desire to avoid what it considered to be the harmful implementation of state-provided care.

The lawyers for the CMA, who included Peart and Hassard from *Goodall v. Brite* and *Pacific Health*, argued that CSB's nonprofit status was essentially a workaround for a commercial enterprise. In briefs before the Fourth Appellate District prior to the California State Supreme Court, they argued that the entity's nonprofit status was simply a shield for profit-seekers, writing, "Simply stated, this case involves the fundamental question of whether or not the public policy that forbids corporate and lay practice of medicine may be circumvented by an elaborate hocus-pocus that puts before the public a 'non-profit' front, and conceals behind this noble (but corporate) front an astute businessman controlling, owning, and profiting from the professional medical services rendered in the 'non-profit' name."[193] Sixteen years earlier, Peart, Hassard, and the CMA generally had argued in *Pacific Health* that corporations operating for a profit could not practice medicine. Confronted with a technical legal switch where the organization in question was incorporated under a different statute as a nonprofit, they argued that the legal veil should not be allowed to obscure its true profit-seeking nature.

CSB was organized under the general nonprofit corporation law in 1939, rather than the for-profit corporation law. CSB both billed the patients and collected those bills for services performed by doctors.[194] CSB's incorporation as a nonprofit organization that did not interfere with physician discretion in relationships with patients proved to be dispositive in the ruling that the CSB was not a corporation illegally engaged in the practice of medicine.[195]

The decision in favor of CSB legitimizing prepayment models had important implications for the provision of medical services across California.[196] As the Court highlighted, not only Kaiser Permanente but also the CMA's California Physicians Service (CPS) were organized through the same statute as CSB, so a decision whether or not CSB was in violation of California state law would have an existential impact on all three organizations.[197] Although Kaiser Permanente was not a litigant, it did file an amicus curiae brief and could have faced major challenges, or even been shut down, had the outcome of the litigation been adverse to CSB.

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[192] Thelen, Marrin, Johnson & Bridges, Attorneys for Amicus Curiae, Kaiser Foundation Health Plan, "Amicus Curiae Brief of Kaiser Foundation Health Plan In Support of Respondents," in California State Archives, *Complete Service Bureau v. San Diego County Medical Society*, 43 Cal. 2d 201 (1954) Supreme Court of California, Case # L. A. No. 22535 in Inventory of the Supreme Court of California Records, SF1-SF20398 (1895-1960), *passim*, quote on page 8; Thelen, Marrin, Johnson & Bridges, Attorneys for Amicus Curiae, Kaiser Foundation Health Plan, "Answer to Amicus Curiae Brief of A.J. Kennedy" in California State Archives, *Complete Service Bureau v. San Diego County Medical Society*, 43 Cal. 2d 201 (1954) Supreme Court of California, Case # L. A. No. 22535 in Inventory of the Supreme Court of California Records, SF1-SF20398 (1895-1960), *passim*.

[193] Gray, Cary, Ames & Frye; Brooks Crabtree, Esq.; Peart, Baraty & Hassard, "Appellants' Closing Brief, District Court of Appeal, State of California, Fourth Appellate District," in California State Archives, *Complete Service Bureau v. San Diego County Medical Society*, 43 Cal. 2d 201 (1954) Supreme Court of California, Case # L. A. No. 22535 in Inventory of the Supreme Court of California Records, SF1-SF20398 (1895-1960).

[194] *Complete Service Bureau v. San Diego County Medical Society*, 206.

[195] *Complete Service Bureau v. San Diego County Medical Society*, 208-210.

[196] "High Court Approves Medical Plan," *Los Angeles Times*, July 13, 1954, 33.

[197] *Complete Service Bureau v. San Diego County Medical Society*, 209-210; "Affairs of State: High Court Upholds Practices of San Diego Medical Group," *The Peninsula Times Tribune*, July 14, 1954 at 18; Henry MacArthur, "Supreme Court Indicates Monopoly Ban Even In Medical Profession," Daily Independent Journal (San Rafael, CA), July 16, 1954, at 8; "State Supreme Court Hands Down Ruling Striking at Monopoly By California's Medical Ass'n," Ukiah Daily Journal, July 21, 1954, 13.

As it turned out, Kaiser Permanente (and CPS) survived the threat. More than twenty years after Sidney Garfield had gone out into the desert east of Los Angeles to provide care to aqueduct workers, the legal right of a nonprofit to coordinate care through a prepayment closed panel system was enshrined in state judicial precedent. There had been ostracism, fractious conflict over union contracts, and intense litigation, but finally Kaiser Permanente and its model were legally secure.

On an occasion earlier in his crusade, Garfield had been at a meeting attended by the President of Stanford University, Dr. Ray Lyman Wilbur. Interested to get the president's thoughts on prepayment care and the medical profession's reaction, Garfield asked Wilbur, "Why are all the doctors all against this?" Wilbur replied, "Young man, you're not wearing a crown of thorns." Anything that was different, he went on, would always encounter objections. If Garfield was indeed doing something good, there would undoubtedly be trouble. Reinvigorated, Garfield kept going. But it had been a tumultuous twenty years with ups and downs and doubts and victories.[198]

And always, at least as important—if not more important—than the expansion under Kaiser Permanente, was the exclusion. Garfield and Kaiser had covered far more people under a private medical care model than had previously been covered, but they had done so with an explicit intent conveyed multiple times in its early history to stave off the threat of government-sponsored care for all. The aversion of both the CMA *and* Kaiser Permanente to socialized medicine has been apparent throughout the second part of this chapter because the benefits of their competition never reached those who were unemployed, for whatever reason, and without adequate resources to pay for private coverage. These—the "indigent"—were prevented from gaining access to higher-quality care from institutions better funded than county hospitals in very large part because of the conflict between fee-for-service and prepayment that ensured the provision of high-quality care remained in the private sector. The California state legal system allowed for the expansion of private care at the expense of government-sponsored alternatives.

Conclusion

J.C. Smith never became a real estate agent. This "plucky" kid who was "a dear boy, a precious boy," with a permanent physical impairment never got the chance to pursue his dream career because of the relationship between employment, disability, and health care in California. Private providers would not cover him, and in fact in *Goodall v. Brite* they took away sources of funding from potential donations that might have helped him. Kaiser Permanente expanded coverage, but not to cover the unemployed and disabled. At the age of 48 J.C. Smith died in a nursing home.[199]

The triadic relationship between employment, disability, and health care that prevented J.C. Smith from living the life he wanted was quite literally defined and constructed by the California state legal system. Sponsors of private options not only worked hard to restrict competition, but also to expel those patients that might need their care the most—people like J.C. Smith. The state's medical profession, legislature, and judiciary worked together to create a category of those who were unemployed and considered disabled who did not have access to quality care.

California statutes and judicial decisions impacting health care forced those who were unemployed into under-resourced and understaffed state health care apparatuses. The

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[198] "Cecil Cutting, MD" interview, 6.

[199] Thorner, oral history, 16.

development of private models based on prepayment helped provide more workers with dependable health care, but those who were not employees were left to depend on the availability of state health care entities. In the 1960s and 1970s, this dynamic, in which those with employment received private care and those without employment were left reliant on limited state care, if any care at all, would eventually pit disability rights activists against state institutions when framing their rights claims. They would protest and advocate against state institutions because those were the institutions to which they had been relegated. They would give much less attention to the private care world reserved for the employed and those deemed "employable." After all, they had never been allowed into that world.

Despite litigious maneuvering by the CMA and private doctors, in 1954 prepayment group plans were eventually legally sanctioned by the California Supreme Court in *Complete Service Bureau v. San Diego County Medical Society*. Costs were lowered as competition from Kaiser Permanente forced the private sector to embrace prepayment. Sidney Garfield's long struggle demonstrated the benefits of private competition in action, and also the costs. Competition forced down prices; it expanded medical care to those who otherwise might not have received it. At the same time, the parties who fought each other so furiously united in their mutual disdain for government-provided medicine. Private doctors operating in the traditional fee-for-service model opposed government intrusions on their domain through their litigation in *Goodall v. Brite*; and at the same time their fierce rival, Henry Kaiser, harshly criticized the possibility of government provided medicine. These enemies in the private sphere both opposed public-funded care.

The CMA and Kaiser Permanente may have fought inside and outside the courtroom, but this conflict still created a two-tiered system where those who were employed and had resources could enjoy private care for a lower cost, while those without employment and fewer resources were forced into underfunded hospitals and state agencies. These legal developments may have lowered costs for those who could afford it, but they constructed a segregated health care apparatus that subjected doctors like Juliet Thorner and patients like J.C. Smith to deeply inadequate health care institutions and woefully few opportunities to do better.

Chapter 3: Cowell Hospital and the Activist Origins of Independent Living

This third chapter is split into three sections. The first section explores theoretical understandings of the medical and social models of disability. It considers arguments in favor of framing disability in each way—some argue that disability should be understood solely as a social obstacle, others that there is merit to a conception of disability as a medical condition, and others that the best approach is a combination of both. I discuss this debate to show how it played out in real time through the lived experience of activists in Berkeley during the 1960s and 1970s. I then discuss how these different perspectives were crucial to understanding the relationship between the institutions related to disability and the people themselves who deal with disability. The second section examines state institutions such as the California Department of Rehabilitation (CADR) and the Student Health Services at the University of California through the use of records and reports from their archives, and asks how these institutions developed alongside activist movements. The third section analyzes the early efforts of activists in changing the conception of what it meant to be disabled in the 1960s and 1970s. This struggle occurred at universities in particular as activists became politically conscious and aware of an existing community around them that could mobilize to ensure their demands were met. I show how students with disabilities came to understand the relationship between the state and the individual through entities such as the Residence Program at U.C. Berkeley's Cowell Hospital and the Physically Disabled Students' Program (PDSP). They learned that the state could impose restrictions and provide accommodations for people with disabilities, which could expand or contract those individuals' freedom. The story of Cowell, Berkeley, PDSP and the Centers for Independent Living is a story of individuals who strove for individual freedom by working with and against the state for an expansion of freedom, and then entered the halls of state power to steer those same expansions of freedom. This chapter addresses the state as both prohibitor and creator of opportunities for those with disabilities. It is not a simple story of activists "rebelling against the machine," it is a story of how they learned to work with the machine and eventually to become the mechanics.

Years after his activism at U.C. Berkeley and in state government during the 1960s and 1970s, Jim Donald was a lawyer helping evict tenants who had not paid their rent. Donald was a quadriplegic as a result of a car accident, and he used a wheelchair for mobility. When issuing an eviction notice one day, the tenant said he was going to ignore it, and Donald replied, "Ignore me, and I'll own your truck." Furious, the tenant reached down, grabbed Donald's shirt, and brought his fist back to punch him. Rather than fear, the immediate thought that crossed Donald's mind was "I've integrated!" Donald was relieved that he was no longer anything "special," and the threat of violence showed he was not being treated differently because of his disability.[200]

Reflecting on the second half of the twentieth century, Donald claimed that the legislative change instigated by activists altered public conceptions of what it meant to be "disabled." For Donald, the Disability Rights Movement of the 1960s and 1970s proved that law can change public morality. He stated, "If you get the law, society starts changing, and then it becomes the

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[200] Jim Donald, Oral History in *University of California's Cowell Hospital Residence Program for Physically Disabled Students, 1962-1975: Catalyst for Berkeley's Independent Living Movement*, Regional History Office, The Bancroft Library, 74-76, 109-111.

norm. Can you imagine now saying that the disabled aren't allowed into a public accommodation because they're disabled? You know, it's inconceivable. But it changed because of the laws."[201] When further reflecting on the political struggle, Donald went on to say, "I see it as a battle that is won. I don't think there's any doubt we're integrated into society… We're a part of the establishment. We've got our rights, and if they're violated we can sue for it, which we do all the time, with success and failure."[202]

This chapter of my dissertation will assess Donald's claim that the public understanding of disability has changed with changes in laws. It will do so by starting with the activists and their adversaries in the 1950s and 1960s to understand how state institutions in California perceived disability; and how the activists were trying to change the conception of what it meant to be disabled according to state institutions and society broadly.

These interactions between activists and state institutions show a sharp distinction between rehabilitative medical-based treatments of disability, and alterations of social environments. In 1950, Californian state institutions sought to alter the individual with the disability; after the 1960s and 1970s, those institutions such as the California Department of Rehabilitation (CADR) began to understand disability as a product of social environments. Disability theorists have argued over the extent to which disability should be attributed to medical conditions and social environments. Disability activists were having this debate in their daily lives, both among themselves and with the institutions and systems surrounding them.

I. Debating the Merits of the Medical Model, Social Model, and the Capabilities Approach

Before proceeding further, I want to emphasize that I recognize that physical and mental disabilities are not the same and I do not mean to conflate the two. It can be argued, and has been argued, that no two disabilities are the same, and there is certainly merit to that point. There are of course major differences in disability within individual categories and across the entire concept of disability. There are differences between physical and mental disabilities, as well as differences within certain conditions; for example not everyone experiences autism or cerebral palsy in the same way. All disabilities, and all people considered disabled, cannot be understood as a monolith. But the following discussion is meant to consider the extent to which any deviation from the "normal"—whether it be mental or physical—is a product of social construction or an actual existing impairment that detracts from opportunities. This debate has important implications for the role of the state and law in both providing opportunities and removing obstacles for those with disabilities. The theorists and commentators engaged in this debate push readers to consider the role of the state and law in providing opportunities based on any form of disability.

The Disability Rights Movement of the 1960s and 1970s has been framed as a shift from the medical model focusing on the individual's impairment as a medical condition to the social model focusing on the environment and attitudinal barriers.[203] Recent scholarship in disability

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[201] Jim Donald, Oral History, 109-111.

[202] Jim Donald, Oral History, 124. Paul Longmore also has a position stating that the affirmation of rights for people with disabilities to access buses was a major shift in the minds and attitudes of Americans generated by the Disability Rights Movement, see Paul K. Longmore, "Disability Scholar and Activist, Historian of Early America" conducted by Ann Lange in 2006, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2008, 164.

[203] Samuel R. Bagenstos, *Law & the Contradictions of the Disability Rights Movement* (New Haven: Yale University Press, 2009), 18-20; Samuel R. Bagenstos, *Disability Rights Law: Cases and Materials, Second Edition* (St. Paul: Foundation Press, 2014), 4; Berkowitz, *Disabled Policy*, 8-9; Eric Garcia, *We're Not Broken: Changing*

studies has debated the merits of framing disability as a social or medical phenomenon. Some scholars have argued that disability is primarily a label of social oppression, rather than any condition intrinsic to the individual. The environment is the sole reason that individuals considered disabled have struggled to function in modern society, and social oppression exiles those individuals from their communities and excludes them from economic opportunities.[204] Arguments in this vein stress that rather than attempt to "cure" a medical condition, medical experts and society more generally should attempt to support those with disabilities in living fulfilling lives, and centralize their own individual autonomy not social or medical understandings of who they are.[205] Social stigma and perceptions of inferiority create disability; there is too wide a range of human behavior, physical capacity, and mental cognition for any one type of person or category to be considered "normal."[206]

Within this group arguing against medically-driven conceptions of disability, some scholars have stressed the role of capitalism in creating disability.[207] A failure to see the true

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the Autism Conversation (New York: Harvest, 2022) 44, 111; Paul K. Longmore and Lauri Umansky, "Introduction," in *The New Disability: American Perspectives*, eds. Paul K. Longmore and Lauri Umanski, (New York: New York University Press, 2001), 12; Ruth O'Brien, "From a Doctor's to a Judge's Gaze: Epistemic Communities and the History of Disability Rights Policy in the Workplace," 35 *Polity*, 329, 337; Michael Oliver, *Understanding Disability: From Theory to Practice, Second Edition* (New York: Palgrave Macmillan, 2009), 42-43; Larry M. Logue and Peter Blanck, *Race, Ethnicity, and Disability: Veterans and Benefits in Post-Civil War America* (New York: Cambridge University Press, 2010), 1-2; Harlan Hahn, "The Politics of Physical Differences: Disability and Discrimination," *Journal of Social Issues* 44 (1988), 39-40; Sharon Barnartt, Kay Schriner, and Richard Scotch, "Advocacy and Political Action," in in *Handbook of Disability Studies* eds. Gary L. Albrecht, Katherine D. Seelman, and Michael Bury (Thousand Oaks: Sage Publications, 2001), 430-431; Eric Garcia, *We're Not Broken: Changing the Autism Conversation* (HarperCollins: New York, 2021), 44; HEYER; Liz Moore, "I'm Tired of Chasing a Cure," in *Disability Visibility: First-Person Stories from the Twenty-First Century* ed. Alice Wong (New York: Penguin Random House, 2020), 75.

[204] See, for example, James I. Charlton, *Nothing About Us Without Us: Disability Oppression and Empowerment* (Berkeley: University of California Press, 1998), 25, "My analysis… throughout this book centers on the political-economic and sociocultural relationships born out of these times and how they have developed differently in different economic zones and cultures. Essentially, I will argue…that these formations now not only stand as barriers to progress but also are the basis for peoples' oppression…"; Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: New York University Press, 1998), 2-3, attributing the field of Disability Studies to reframing disability as a social phenomenon, "By refusing the medicalization of disability and by reframing disability as a designation having primarily social and political significance, disability studies points to the inadequacy of the entire curriculum with respect to the study of disability"; and G. Albrecht and J. Levy, "Constructing Disabilities as Social Problems" in *Cross National Rehabilitation Policies: A Sociological Perspective* (Beverly Hills: Sage Publications, 1981), 14, "We contend that disability definitions are not rationally determined but socially constructed. Despite the objective reality, what becomes a disability is determined by the social meanings individuals attach to particular physical and mental impairments. Certain disabilities become defined as social problems through the successful efforts of powerful groups to market their own self interests."

[205] Eric Garcia, *We're Not Broken: Changing the Autism Conversation* (New York: HarperCollins, 2021), xiii-xv, 2, 10, 12, 20, 23, 36-37, 114-120.

[206] Roy Richard Grinker, *Nobody's Normal: How Culture Created the Stigma of Mental Illness* (New York: W.W. Norton & Company, 2021), xv-xix, xxiii.

[207] Grinker, *Nobody's Normal*, xxv, 5, 8, "One of [the several historical patterns that can help us understand the dynamics of the stigma of mental illness] is *capitalism*. In capitalism, the inability to work became the quintessential disease of modernity, and the source of stigma of mental illness. Stigma does not derive from ignorance or lack of knowledge, but rather from the conception of mental illness as the sign of the idle, a personality incapable of achieving the ideal: producing for oneself and the economy." (Quote on page xxv); Marta Russell and Ravi Malhotra, "Capitalism and the Disability Rights Movement," in *Capitalism & Disability* ed. Keith Rosenthal (Chicago: Haymarket Books, 2019), 2, "…we take the view that disability is a socially created category derived from labor relations, a product of the exploitative structure of capitalist society: one which creates (and then

capacity of all people develops which emphasizes a flawed individual rather than a flawed society.[208] It is the systems and institutions, rather than minds and attitudes alone, that create disability.[209] This does not completely disregard the role of health and medical condition, but instead places the onus on the social factors that contribute to a different treatment based on health and medical condition.[210]

Others claim that the social model can be limiting or even debilitating depending on how it is implemented. These scholars argue that there is a "relational" understanding of disability—to frame it bluntly, social conditions and the individual's condition both contribute to disadvantages of disability.[211] Thomas Shakespeare in particular argues against undue emphasis on social conditions and environmental barriers to disability. The individual's impairment itself is a major contributing factor to the disadvantages and exclusions that disabled people face; those disadvantages and exclusions are not entirely a result of social conditions alone.[212] Shakespeare argues that unlike discrimination on the basis of race or gender, there is in fact a biological dimension to disability that contributes to disabled people's disadvantages.[213] Opposing a solely negative conception of medicalization, he argues that medical diagnoses and interventions allow for positive allocation of services and accommodations, such as accessible parking, attendant care, and pension benefits.[214] Shakespeare's criticism of social model theorists and postmodern approaches to disability, leads him to a "critical realist" approach:

> "Critical realism means acceptance of external reality: rather than resorting to relativism or extreme constructionism, critical realism attends to the independent existence of bodies which sometimes hurt, regardless of what we may think or say about those bodies…critical realists distinguish between ontology (what exists) and epistemology (our ideas about what exists). They believe that there are objects independent of knowledge: labels describe, rather than constitute, disease…while different cultures have

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oppresses) the so-called *disabled* body as one of the conditions that allow the capitalist class to accumulate wealth."; Michael Oliver, *Understanding Disability: From Theory to Practice, Second Edition*, (New York: Palgrave Macmillan, 2009), 131, "In fact…disabled people have no choice but to attempt to build a better world because it is impossible to have a vision of inclusionary capitalism; instead we need a world where impairment is valued and celebrated and all disabling barriers are eradicated" and 156, "My own deliberations on the exclusion of disabled people from modern societies unequivocally locates capitalism as the main villain."

[208] Charlton, *Nothing About Us Without Us*, 27; Oliver and Barnes, *The New Politics of Disablement*, 112.

[209] Michael Oliver and Colin Barnes make this distinction, differentiating between "social construction" and "social creation", they write: "The social constructionist view remains rooted at the ideological level and sees the problem as being located within the minds and attitudes of able-bodied people, whether individually (prejudice) or collectively generated, through the manifestation of hostile social attitudes and the enactment of social policies based upon a tragedy view of disability. Alternatively, the social creationist view sees the problem as located within the institutionalized practices of society, leading to the notion of institutional discrimination which has been used in a variety of settings." Oliver and Barnes, *The New Politics of Disablement*, 125.

[210] Oliver, *Understanding Disability*, 47; Charlton, *Nothing About Us Without Us*, 23-27, 35-36.

[211] See Thomas Shakespeare, *Disability Rights and Wrongs Revisited, Second Edition* (New York: Routledge, 2014 (2016)), 5, "To offer a crude headline, people are disabled by society *and* by their bodies." Emphasis in original.

[212] Shakespeare, *Disability Rights*, 28, 30, 33, 40-41, "Disabling barriers make impairment more difficult, but even in the absence of barriers, impairment can be problematic." Quote on page 33.

[213] Shakespeare, *Disability Rights*, 49, "Gender, race and sexuality have minimal biological underpinning. However, disability always has a biological dimension that usually entails limitation or incapacity, and sometimes frailty and pain."

[214] Shakespeare, *Disability Rights*, 63-66.

> different views or beliefs or attitudes to disability, impairment has always existed and has its own experiential reality."[215]

Shakespeare thus argues for a line between the condition of the individual and social forces surrounding that individual. The impairment can exist and be detrimental regardless of the social environment or attitudes.

One place we see these two perspectives collide is the debate over independence and coercion with respect to mental conditions, such as schizophrenia and autism. Although this discussion is not about physical disability, which Cowell Residence students primarily experienced, the positions on each side speak to the extent to which public institutions should play a role in coordinating, and sometimes determining, the lives of those considered disabled.

Arguably, a complete lack of institutional involvement for the sake of independence can have devastating consequences. Jonathan Rosen writes of his childhood friend, Michael Laudor, who had been diagnosed with schizophrenia. Rosen argues that Laudor needed an "asylum"—not the archaic institutions that abused those considered mentally disabled, but a place that would help him manage the delusions that ultimately led him to kill his fiancée. Laudor had a brilliant mind that gained him access to a prestigious consulting firm and law school, but that mind also generated thoughts of paranoia and violence. Rosen's experience with his childhood friend showed him that some medical interventions, even as extreme as institutionalization, were not responses to "social constructs," but instead necessary assistance to those who needed it. Rosen writes about how, before the killing, while he was in graduate school at UC Berkeley, "learning from Foucault that mental illness is a 'social construct' invented to imprison enemies of the state," at the same time his friend Laudor had been confined to a psychiatric unit after threatening his mother with a knife and accusing her of being a Nazi.[216] She had called the police and he had been taken away to a "locked ward." When Rosen visited Laudor at the ward, he "found it impossible to pretend that [Laudor] was suffering from a 'social construct.'" Rosen did not like the hospital, but also did not recognize it as an oppressive tool of the carceral state. Rosen also writes of how, during an interview with Laudor about how he went from a psychiatric ward to Yale Law School, Laudor was asked about violence and schizophrenia. Laudor said that this was a "common and painful stereotype." Rosen appreciated the indignation, but also remembered that before medication, Laudor had wielded a knife out of fear that his parents were Nazis. Rosen also writes of a volunteer who helped the homeless; one woman in particular was living on the street for ten years. The volunteer did not want to institutionalize her out of respect for her dignity and autonomy, but the police eventually did. After hospitalization and other interventions, the homeless woman became stably housed and began working. When she later saw the volunteer after her recovery, she called him profane names and accused him of leaving her on the street for ten years. She said, "If I were bleeding, you would have taken me in. But since it was my brain, you left me out there." Rosen does not argue for drastic and invasive interventions at all times, but he insists that people like his friend, Michael Laudor, and Laudor's fiancée, Caroline Costello, could have been saved with medical interventions by forced hospitalization before, rather than after, the violent attack. Out of fear of temporary intervention and forced hospitalization for months or weeks, Michael Laudor is now spending the rest of his live under forced hospitalization in a secure psychiatric facility.[217]

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[215] Shakespeare, *Disability Rights*, 73

[216] David Bergner expresses a similar interpretation of Michel Foucault in his *The Mind and the Moon: My Brother's Story, the Science of Our Brains, and the Search for our Psyches* (New York: HarperCollins, 2022), 46.

[217] Jonathan Rosen, "American Madness," *The Atlantic*, May 2023, 54-68.

In *Far From the Tree*, Andrew Solomon writes that parents of children with autism can become frustrated with those who argue that positive framing changes the experience of those with disabilities. Scholars who seek to change how people view those with autism or Down syndrome by imposing lesser social meaning on it are actually not helpful and can even be counterproductive. Solomon writes about the poem "Welcome to Holland," which essentially illustrates that having a child with a mental disability is analogous to thinking you were going to vacation in Italy, but your flight was redirected to Holland. The experience might not be what was expected, but with the right mindset you can still enjoy and appreciate it. Some parents raising children with severe conditions find this sentiment insensitive—one mother of an autistic child wrote "Welcome to Beirut," in response, saying that the experience is more like landing in the middle of a warzone.[218] Social sentiments, attitudes, and conditions will not necessarily change the experience of the parent or their child living with a disability.[219] The lived experience of having what is considered to be a disability and the social construction of disability are not aligned.

Jill Escher writes about her experience as a parent of two autistic children in an article in *The Free Press* stating that the "recent rise of the 'neurodiversity' identity movement, where autism is reinvented as a natural difference to be celebrated, not investigated, prevented, or treated, has helped spread a fairy dust of complacency over the autism world…It's become de rigeur to normalize autism rather than treat it as the national emergency it most certainly is." She writes of how Lee Wachtel, medical director of the Neurobehavioral Unit at Kennedy Krieger Institute in Baltimore, describes her workplace that treats autism patients as a "warzone." Escher argues that "disability policies based on fantastical conceptualizations of ability are creating cruel consequences for our most vulnerable." Like Andrew Solomon, Escher emphasizes the importance of social public resources and services as parents of autistic children and adults die. She writes of the role parents take on as caretakers: "As we lose autism parents, we lose nearly everything that makes life possible for every person disabled by autism: the housing provider, the 24/7 supervisor, the program manager, guardian, trustee, financial manager, benefits manager, advocate, cook, driver, hygienist, housekeeper, launderer, medical supervisor, recreation provider, interpreter, iPad fixer, handyman, protector from abuse and neglect, and of course, the main source of love and nurturing. It's the equivalent of more than a dozen jobs if not more, plus jobs money can't pay for." The condition of autism is not socially constructed, it is very much lived in the biological, neurological, and familial realities of individuals and their relatives who are experiencing it. She ultimately argues that progress, aid, and solutions cannot be reached if the rhetoric surrounding autism is that of normalization and neurodiversity "fairy tales" rather than the visceral reality of what it means for individuals and those around them to recognize the challenges and struggles of living with autism.[220]

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[218] Andrew Solomon, *Far From the Tree: Parents, Children, and the Search for Identity* (New York: Scribner, 2012) 169-170, 223.

[219] For another example of this argument, see Freddie deBoer, "The Gentrification of Disability," at https://freddiedeboer.substack.com/p/the-gentrification-of-disability. deBoer argues that framing autism in a positive light based on some people's experiences of it can be severely limiting to those with more severe conditions that prevent them from basic social interactions and functions. If the perspective on a condition that is considered disabling is overly positive based on examples of those excelling in the socio-economic sphere, that framework pushes aside the stories and experiences of those who have not excelled and need assistance.

[220] Jill Escher, "The Autism Surge: Lies, Conspiracies, and My Own Kids," *The Free Press*, July 20, 2023, https://www.thefp.com/p/the-autism-surge-lies-conspiracies. Escher also reveals how disability can be a deadly reality, despite the parents' best efforts. When Feda Almaliti rushed into a fire to save her autistic 15-year-old son,

Paul Longmore, a major disability rights activist, also does not perceive the line between medical and social models to be clear and obvious. He contended that the emphasis on social construction went too far, and that there are intrinsic difficulties inherent in the disability experience. Longmore states,

> "I think also, though, that the disability rights movement may have carried that too far because it ends up in a lot of ways masking the actual inherent difficulties and limitations and the real suffering of people with certain kinds of conditions, so what ends up happening with, among disability rights activists is in private they'll talk about the real struggles physically and in public they'll talk about the civil rights issues. Well, we need to talk about the civil rights issues, but I think it's seriously problematic that these two public and private discourses are so separate from one another."

He goes on to say that he had a conversation with an activist at a rally in San Francisco, and the activist confessed that he or she was struggling immensely with health issues related to their disability. The activist then proceeded to claim at the podium that all of their disability issues were due to social constructs. Longmore attributes this to political pragmatism, stating,

> "Probably, well, the certainly unspoken, possibly unconscious, assumption is, we cannot take the risk of talking publicly about these inherent difficulties or this innate suffering in some disabling conditions because if we do, nobody is going to hear what we say politically about prejudice and discrimination and civil rights and access and accommodations."

There is a strain between recognizing intrinsic impairments that are not social constructs, as well as the social impositions that further burden people who already struggle with their health or mobility.[221]

Daniel Bergner writes about individuals in his life who have conditions such as bipolar disorder, psychosis, and depression, and the promise of psychiatric medicine in "curing" them of these conditions and bringing them back to "normal."[222] Bergner argues that this violated the will and autonomy of individuals like his brother, who was detained when he tried to leave Seattle and fly to Poitiers, France after feeling a connection to Joan of Arc's experience there because that was where he was born.[223] Bergner's sympathy for his brother and skepticism of the psychological medication conflicts with his recognition that his brother has struggled and been homeless. When his brother calls to tell Bergner that he will not be at his wedding, Bergner confesses relief.[224]

In an article for *The Atlantic*, Emil Sands discusses his experience with hemiplegia, a form of cerebral palsy that affects one side of the body. Throughout the piece reflecting on his childhood, Sands grapples with two approaches to his experience with hemiplegia: the "proper one," where he owns the condition and embraces, it; and his "natural response," which is to regret it and try to conceal it.[225] He spent his childhood yearning for "normalcy," looking at his body and insisting that he was not the person looking back at him in the mirror, and exercising to

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Muhammed, he refused to move. Escher writes, "When the firefighters found their bodies, Feda was embracing Mu."

[221] Paul Longmore, oral history, 153-154, first quote on page 153, second quote on page 154.

[222] Daniel Bergner, *The Mind and the Moon: My Brother's Story, the Science of Our Brains, and the Search for our Psyches* (New York: HarperCollins, 2022), 19-20, 25-26, 132.

[223] Bergner, *Mind and the Moon*, 149-153.

[224] Bergner, *Mind and the Moon*, 278

[225] Emil Sands, "Struck on One Side: Society Tells Me to Celebrate My Disability. What If I Don't Want To?" *The Atlantic*, March 2023, 62.

mitigate the effects of the disability.[226] After this childhood of hiding any sign that he had what is considered to be a disability, he still does not tell anyone that he has a disability out of fear that people will like him less. Yet this is not a solid, final conclusion of his outlook on his condition. Sands never resolves the original dilemma between a "proper" embrace of his body and a "natural" inclination to hide it. He ends by saying, "I am not sure I want to hide anymore. I'd rather embrace my disability than fear its fallout. But it would be a lie to say I love every part of my body. I am still grappling with the ways I have been made to feel that my body does not belong—and with the conviction that it is easier for everyone that I be a failing normal rather than a normal disabled."[227] Sands's experience illustrates that there is not a neat and tidy delineation between a full embrace of one's body and the ongoing tendency to try to hide it. His social environment changes, the impact of his condition on his ability to appear "normal" changes, and his subjective perspective on the condition changes; all of these variables are in constant flux to the point that no clear resolution is achieved. That can be the uncomfortable and unsatisfactory conclusion—that there is no concise answer to the effect of social environment and medical impairment on the experience of having a body considered disabled.

Sands, Solomon, Rosen, Escher, Longmore, and Bergner all recognize that people with disabilities should be treated with dignity and compassion just as all human beings should, but they also push back against the narrative that disability is only a social construct or a product of a capitalist economy and there is no basis for it in biological fact, nor should it be addressed by medical interventions.

Amartya Sen and Martha Nussbaum have applied their theory, the "Capabilities Approach," to disability. Sen explicitly contrasts the theory with utilitarian assessment, the capabilities approach assesses individual advantage based on "a person's capability to do things he or she has reason to value." For Sen, the capabilities approach is not about a specific transcendental design, but instead focuses on using information to assess comparable opportunities and capabilities available to individuals at a given time and location. [228] Applied to the concept of disability, Sen stresses the importance of income for those with disabilities which are magnified through the "conversion handicap." People with disabilities often have to convert limited income into services and resources that others do not need. This compounds the restricted capability and opportunity to pursue a life they value.[229]

Nussbaum ties the capabilities approach to an assessment of outcomes, seemingly in a utilitarian vein. She contrasts her position with Sen's by stating that Sen focuses on comparative quantitative measurements, while Nussbaum emphasizes the importance of core human entitlements that should be respected by all governments in accordance with a bare minimum of human dignity.[230] She writes:

> "The capabilities approach is like a criminal trial. That is, it starts from the outcome: with an intuitive grasp of a particular content, as having necessary connection to a life worthy of human dignity. It then seeks political procedures (a constitution, various allocations of powers, a certain type of economic system) that will achieve that result as nearly as possible, although it seems likely that such procedures will change over time and may

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[226] Sands, "Struck on One Side," 61-63.
[227] Sands, "Struck on One Side," 65.
[228] Amartya Sen, *The Idea of Justice* (Cambridge, Mass.: Harvard University Press, 2009), 231-232
[229] Sen, *The Idea of Justice*, 258-260.
[230] Martha Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership*, (Cambridge, Mass.: Harvard University Press, 2006), 70

> also vary with the circumstances and history of different nations. Justice is in the outcome, and the procedure is a good one to the extent that it promotes this outcome."[231]

Nussbaum treats the capabilities approach as a floor of human opportunity and dignity, above which it offers no value. For Nussbaum, the capabilities approach says nothing about the inequalities and advantages above that floor. Once those basic standards have been met, the capabilities approach offers no further insight. The list of basic needs that must be met to align with the capabilities approach is not comprehensive and is subject to modification, but the top five include: life, bodily health, bodily integrity, senses, imagination and thought, and emotions.[232] Importantly, the capabilities approach allows for variation of needs and resources depending on the individual.[233]

Nussbaum takes issue with the emphasis on mutual advantage in social contract theory and argues that people are committed to the wellbeing of others around them.[234] Further, she stresses that an emphasis on money is not enough—if someone operating a wheelchair is given large sums of money, that still does not necessarily provide them access when architectural barriers are in their way. Removal of those obstacles requires public intervention and alterations to the environment, which demands more than subsidizing people with disabilities. This would also involve reliable attendant care for those in need, to fulfill the capabilities requirement for both caregiver and the individual with the disability. Caregiving can be a demanding job for those who do it, and if it is a family member, relative, or close friend, it can often be done without any monetary compensation. A moral social order would provide a basic level of attendant care to afford basic opportunities to the individual with disabilities and also uncompensated caregivers.[235] There needs to be a political effort to provide basic needs for all citizens, which may involve higher levels of expenditure for those with disabilities.[236]

While both sides of the argument make strong points—one stressing social and systemic causes, the other emphasizing the importance of the physical body and mind—they are in danger of missing the forest for the trees. Both the medical model's emphasis on rehabilitation and the social model's removal of environmental barriers can work in tandem to pursue the goal of expanding autonomy and opportunity for those considered disabled. The creation of a residence for students with disabilities in Cowell Hospital at Berkeley in the early 1960s and the development of the Independent Living Movement in the late 1960s and early 1970s both expanded the autonomy of those considered disabled. An examination of the California Department of Rehabilitation (CADR), Cowell Hospital, and the Physically Disabled Students' Program (PDSP) contributes to a more nuanced understanding of the relationship between state institutions and people with disabilities. State officials could serve as both obstacles and conduits for access and opportunity depending on their choices. They often served as vital resources for people seeking to attend university who had been previously limited by those very same institutions. Disability activists who entered CADR in the 1970s would learn from their experience at university in the 1960s in creating opportunities for the disabled community in the last quarter of the twentieth century. The activism and advocacy of students with disabilities in California during the 1960s and 1970s offers insight into how social conceptions of disability

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[231] Martha Nussbaum, *Frontiers of Justice*, 82.
[232] Martha Nussbaum, *Frontiers of Justice*, 75-76.
[233] Martha Nussbaum, *Frontiers of Justice*, 88
[234] Martha Nussbaum, *Frontiers of Justice*, 157-158
[235] Martha Nussbaum, *Frontiers of Justice*, 167-170.
[236] Martha Nussbaum, *Frontiers of Justice*, 190.

could change, while at the same time showing the stark reality of a lived experience with a physical impairment that would not be altered along with that social conception of disability. Institutions and systems may be altered, but it often takes internal actors and external activists to shape those entities in ways that improve the lives of those with disabilities. Rather than a simple state-vs-activists binary, the experience at U.C. Berkeley in Cowell Hospital and the Physically Disabled Students' Program during the 1960s and 1970s shows how state institutions and officials can also be important facilitators of change.

II: The California Department of Rehabilitation and Cowell Hospital

Charles Grimes was first introduced to Ed Roberts and John Hessler when he visited the Cowell Hospital wing with his friend and roommate Michael Fuss in the summer of 1967. Grimes was desperate for work, and Michael Fuss had met Roberts and Hessler when he was recovering in the hospital after surgery on his intestine, so he knew that they needed attendant services. Fuss had been working for them and told Grimes he could get work there, too.

They walked over to Cowell and first entered John Hessler's room. Hessler was six foot, five inches tall and had a towering personality to match his massive frame. When Hessler was sitting up, he looked to Grimes like "the crown prince of the world…He was god." For the first few minutes Hessler did not acknowledge Grimes; he immediately started giving Fuss instructions about how to help him get up and start his morning routine, even if Fuss was already in the process of doing the requested task. It was only once the entire morning routine was completed that Hessler finally looked over at Grimes and said, "Nice to meet you."

Fuss and Grimes then went to Ed Roberts's room and started his morning routine. Roberts had a much bigger room because it needed to fit an iron lung. The major impression Grimes had upon meeting Roberts was how hairy he was. According to Grimes, "[Roberts] had a beard, and he had fairly long black hair, so it was basically—fur and glasses is pretty much all you saw." Grimes was struck by the explosion of activity in Cowell's residence for students with disabilities, and at the center of it all were Ed Roberts and John Hessler.[237]

The experience of disability rights activists at U.C. Berkeley in the 1960s and 1970s was not only an emergence of a cross-disability political consciousness, but also an illustration of different understandings of how disability was defined and the role that third parties such as state institutions played in contributing to this definition through both aid that expanded possibilities and patronizing restrictions that limited the autonomy of individuals with disabilities. This section outlines the state institutions involved in the interaction between the activists and the state apparatus, and then discusses the positive and negative aspects of that interaction. Roberts and Hessler's residence at Cowell Hospital on campus was the product of two state institutions: CADR and U.C. Berkeley's Student Health Services.

A. California Department of Rehabilitation

The commencement of public health administration in California can be traced to the arrival of goldminers and the physicians who treated them in the second half of the nineteenth century. In 1870, state legislation established a State Board of Health in California, consisting of seven doctors of medicine holding quarterly meetings. After 1905 the Board focused on establishing standards for food and drugs, as well as recording statistics related to public health.

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[237] Charles A. Grimes, "Attendant in the Cowell Residence Program, Wheelchair Technologist, and Participant/Observer of Berkeley's Disability Community, 1967- 1990s," an oral history conducted in 1998 by David Landes, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 15-26.

In 1929, legislation established the Department of Public Health under the purview of the State Board, and it was this department that began to address the needs of disabled individuals in California. The Department of Public Health had a division that addressed "crippled children" by providing medical treatment for parents and guardians unable to do so. Treatment was closely tied to law through the judicial branch; the division would only be able to provide treatment if certified by the superior court of the county in which the child resided.[238] In the second half of the 1930s California was able to expand its public health services with new federal funding from the Social Security Act of 1935. That funding allowed for new hires and an expansion of services at the local level, while the California Public Health Department grew in an unorganized, haphazard fashion.[239]

In the 1950s, California's Department of Education had a Vocational Rehabilitation Section that assessed whether rehabilitation would lead to the individual's education and employment. In the early 1960s the various entities across California that were used to assess disability were streamlined into one single department, the California Department of Rehabilitation. Reports from the Department archives reveal a concerted effort for a narrower focus on rehabilitation at a state-wide level. The Federal Rehabilitation Act provided federal reimbursement for state agencies responsible for vocational rehabilitation, so by combining these different state entities into a new Department of Rehabilitation, those services would be funded in part through federal reimbursement.[240] The emphasis of this department would be assisting individuals with disabilities train for and find employment, rather than provide welfare. Activists would take their experiences with this program and use those experiences to change it from the outside and within so as to frame disability as less focused on rehabilitation and more focused on accessibility for all. These early interactions with state rehabilitative institutions would have a foundational impact on the activists. They were an early sign of how they were perceived by the state and treated before the law.

The relationship between CADR and disability activists in the 1960s was multifaceted. First, and arguably foremost, CADR played an important role in funding the higher education of those considered disabled. CADR provided books, tuition, and transportation for students considered disabled attending university. Budget allocation for these services would have a dramatic effect on the educational experience of students with disabilities. Furthermore, CADR was instrumental in providing the funding necessary to convert the third floor of Cowell Hospital into a residence for students with disabilities. In these ways, CADR was an essential entity in creating and expanding the possibilities for those with disabilities seeking higher education in the

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[238] G P Jones, "Thomas M. Logan, M.D., Organizer of California State Board of Health and a Co-Founder of the California Medical Association." *California and Western Medicine* vol. 63, 1 (1945), 8-9; G P Jones, "The California State Board of Public Health: California's State Board of Health, the Second to Be Established in the United States." *California and Western Medicine* vol. 46, 6 (1937), 400; Halverson, W L. "History of Public Health in California." *Bulletin of the Medical Library Association* vol. 37, 1 (1949), 59-61.

[239] Malcolm Hendricks Merrill, M.D., M.P.H. "A Director Reminisces," an oral history conducted in 1970 by Gabrielle Morris, *Earl Warren History Project*, The Bancroft Library, University of California, Berkeley, 30, 36-37, 40-41

[240] Various Reports, No attributed author/s, in California State Archives – Department of Rehabilitation – F3934:1 and F3934:4, in Administrative Files – Projects, Box 1. A letter from Hale Champion, the Director of the California Department of Finance, to Anthony Celebrezze, the Secretary of the Department of Health, Education, and Welfare, explicitly states that a major motivation behind consolidation of these services into one department is the availability of federal reimbursement.

1960s and 1970s.[241] However, CADR would also place limits on autonomous decision-making of students residing at the hospital. Cowell was where the activists and state institutions would collide, challenging each other's conceptions of what it meant to be disabled and the role the state would play in providing resources and services.

B. Student Health Services and Cowell Hospital

Cowell Hospital was a facility under the umbrella of the Student Health Service at U.C. Berkeley (SHS). The SHS started in the first decade of the twentieth century after the 1906 earthquake and served as an impetus for a health care system at the university. During its first

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[241] Brenda Premo, oral history, 94; Cathrine Caulfield, "First Woman Student in the Cowell Program, 1968," an oral history conducted in 1996 by Susan O'Hara in *University of California's Cowell Hospital Residence Program for Physically Disabled Students, 1962-1975: Catalyst for Berkeley's Independent Living Movement*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 141; Ed Roberts, oral history, 12, 32-35; Dennis Cannon, *Advocate for Accessible Public Transportation in California and Washington, D.C.*, an oral history conducted by Fred Pelka in 2001 in *Shaping National Disability Policy: Transportation Access and Social Security Reforms*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2004, 18; Douglas Martin, oral history, 90; Linda Perotti, "An Employee Perspective on the Early Days of the Cowell Residence Program, Physically Disabled Students' Program, and the Center for Independent Living," an oral history conducted by Kathy Cowan in 1998, Oral History Office, Bancroft Library, U.C. Berkeley, 2000, 117-118; Zona Roberts, "Counselor for UC Berkeley's Physically Disabled Students Program and the Center for Independent Living, Mother of Ed Roberts," an oral history conducted in 1994-1995 by Susan O Hara, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 85-86; James Donald, Student Resident At Cowell, 1967-1968, Attorney and Deputy Director of The California Department Of Rehabilitation, 1975-1982," an oral history conducted in 1998 by Kathryn Cowan in *University of California s Cowell Hospital Residence Program for Physically Disabled Students, 1962-1975: Catalyst for Berkeley's Independent Living Movement*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 76; Judith Heumann, "Pioneering Disability Rights Advocate and Leader in Disabled in Action, New York: Center for Independent Living, Berkeley; World Institute on Disability; and the US Department of Education 1960s-2000," an oral history conducted by Susan Brown, David Landes, Jonathan Young in 1998-2001, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2004, 88, 104-105; Henry Bruyn, "Director, Student Health Services, 1959-1972," an oral history conducted in 1994-1995 by Susan O' Hara in UC Berkeley's Cowell Hospital Residence Program: Key Administrators and California Department of Rehabilitation Counselors, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 5-8; Betty H. Neely, "Recollections of the Director of Student Activities and Programs," an oral history conducted in 1984 by Herb Wiseman in *Disabled Persons' Independence Movement: The Formative Years, 1962-1977*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1987, 20; Arleigh Williams, "Recollections of the Dean of Students," an oral history conducted in 1985 by Herb Wiseman in *Disabled Persons' Independence Movement: The Formative Years, 1962-1977*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1987, 6; Edna Brean, "Nurse Coordinator, Cowell Residence Program, 1969-1975," an oral history conducted in 1994-1995 by Susan O Hara in UC Berkeley's Cowell Hospital Residence Program: Key Administrators and California Department of Rehabilitation Counselors, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 33; Herbert R. Willsmore, "Student Resident at Cowell, 1969-1970, Business Enterprises Manager at the Center for Independent Living, 1975-1977," an oral history conducted in 1996 and 1999 by Susan O'Hara in *University of California s Cowell Hospital Residence Program for Physically Disabled Students, 1962-1975: Catalyst for Berkeley's Independent Living Movement*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 160-161, 170; Hale Zukas, "National Disability Activist: Architectural and Transit Accessibility, Personal Assistance Services," an oral history conducted in 1997 by Sharon Bonney in *Builders and Sustainers of the Independent Living Movement in Berkeley, Volume III*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 116; Herbert Willsmore, "Autobiographical Summary," in Herbert Willsmore Papers, The Bancroft Library, BANC MSS 99/249c, 2; "The Cowell Residence Program, University of California, Berkeley," undated, no author, in Herbert Willsmore Papers, The Bancroft Library, BANC MSS 99/249c, 2-3; Undated grant proposal, no author, description of PDSP, in Hale Zukas Papers, The Bancroft Library, U.C. Berkeley, BANC MSS 99/150c, Carton 2, 2.

twenty years the SHS was located in a small, brown-shingled house on College Avenue that was equipped with twenty beds. Alumnus Ernest V. Cowell died and left $250,000 to U.C. Berkeley to build a hospital. In the late 1920s, the university hired Arthur Brown, Jr., who designed Coit Tower, to be the architect for Cowell Hospital. The hospital opened its doors to patients in 1930.[242] It was in this hospital that students with disabilities would first arrive and live while attending U.C. Berkeley.

i. Ed Roberts

Ed Roberts's activism was shaped by his treatment by the California Department of Rehabilitation. Before attending U.C. Berkeley, Roberts graduated from Burlingame High School despite having to attend classes remotely for most of his time there. Because he could not be out of his iron lung for an extended period of time he attended classes by telephone, which allowed him to hear his teachers and ask questions. Although he was able to finish high school with excellent grades, he still had to push against authority figures to ensure his graduation. He was held back and told he could not graduate due to his failure to complete the driving and physical education requirements—an obvious hurdle given his condition. He and his mother, Zona Roberts, had to appeal directly to the school board for him to graduate. It was a lesson in pushing back by appealing higher up within institutional hierarchies to make change.

The lesson started with the high school counselor, who informed Ed he could not graduate. Zona Roberts had to go over the counselor's head to the principal and superintendent, who sided with the counselor. An assistant superintendent came to their house and told Ed that he should not want a "cheap diploma", which infuriated both Zona and Ed. Zona went even higher and lobbied the superintendent of the entire county of San Mateo, while also reaching out to some contacts she had on the school board. It seems that there was some deliberation about his status behind closed doors because at a school board meeting to discuss Ed's situation Zona was prepared to advocate for his graduation; but that was not necessary, the school board granted the diploma before she spoke. The decision left her speechless and in tears. Her advocacy with the school board and superintendent appeared to have worked, and they had made the decision at some point between her initial advocacy and the school board meeting. Speaking about the conflict with the officials in state institutions, Zona said, "…Ed, in seeing that kind of battle, it was the beginning for him of seeing that things could be challenged and could change."[243] This early fight with state institutions taught Ed not to take "no" for an answer. Appealing to officials higher up in an institution could be effective in achieving his goals.

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[242] Dorothy S. Harvey "A Brief Summary of the Early Years of SHS," Medical Record Department, 1937-1972; Margaret Alter, "Memories of a Cowell Nurse," in *California Monthly*, January, 1954, 17-18, 31-33; "UC Hospital Busy Serving Student Body," *Berkeley Daily Gazette*, May 6, 1954; Robert T. Legge, "University of California Students' Health Center," reprint from *The Pacific Coast Journal of Nursing*, January, 1931, Vol. 27, No. 1; Robert T. Legge, "A Quarter of a Century of Health Work in the University of California Health Service," reprint from *The Journal-Lancet*, May, 1940, Vol. 60, No. 5, 236; Ruby Cunningham, "Cowell Memorial Hospital," in *The Prytanean*, January, 1932, Berkeley, California; "50 years of service: University student health history," in *The Daily Californian*, February 1, 1957, 17; "50-Year Record of U.C. Hospital Hailed," *Oakland Tribune*, February 3, 1957; "Hospital Addition Dedicated," *University Bulletin*, Vol. 9, No. 8, December 5, 1960; "The Way It Was: Images of Berkeley's Architectural Heritage," *Berkeley Voice*, June 29, 1989; all materials located in: Materials relating to the history of Cowell Memorial Hospital and the University of California, Berkeley Student Health Service, Bancroft Library, U.C. Berkeley, CU-527.

[243] "High School Will Graduate Polio Victim in Iron Lung," *San Mateo Times*, January 17, 1959, 2; Ed Roberts, oral history, 30-31; Zona Roberts, oral history, 73-76; Timothy Pfaff, *California Monthly*, February 1985, retyped story by Minnesota's Governor's Council on Developmental Disabilities, 1.

Roberts graduated from the College of San Mateo (CSM) and sought to transfer to a four-year institution. He went to see a counselor at CADR and after running some medical and psychological tests, they rejected him as a client because he was "too disabled to work." Medical doctors evaluated him and claimed that he would not be successful in college. This was one of his early experiences with medical professionals who were more interested in telling him about his condition and his capacities than listening to him talk about his own body. It was only after Jean Wirth, a professor at CSM, and Phil Morse, an administrator at CSM, intervened that Roberts was provided with funding from CADR to attend U.C. Berkeley. Roberts's own testimony as to what he could do was insufficient; it was only after professional counselors advocated for him before CADR officials that he was deemed a feasible CADR client. Roberts learned through this experience that public pressure would be a vital tool in pushing state institutions to change. His struggle with administrators to graduate from high school directly influenced his fighting spirit before CADR; he learned that publicity and appeals to higher positions were necessary to make change.[244] He would take these lessons with him to U.C. Berkeley, where he would push against CADR rules and regulations governing those with disabilities.

Ed, Zona, and counselors from the College of San Mateo traveled to Berkeley and met the Dean of Men[245] Arleigh Williams at Sproul Hall. Williams was their first contact at U.C. Berkeley.[246] Attendants of the meeting recall it differently. Zona recalled that Arleigh said Ed would not be a good fit at U.C. Berkeley. Williams recalled that it was a positive and optimistic meeting, but that there were some concerns over housing and transportation to classes. Ed stated that Williams was both "encouraging and discouraging," because Williams stated that they did not have much experience with students with disabilities, but that it was time that the university did more to include them.[247] Despite conflicting accounts, one fact is certain—Arleigh Williams sent them to talk to Dr. Henry Bruyn the head of U.C. Berkeley's Student Health Services at the time.

Dr. Bruyn had the idea of housing Ed in the Cowell Hospital as a makeshift dorm room that would allow him to attend school.[248] For Bruyn, if a student was accepted based on

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[244] Ed Roberts, oral history, 26-31, Zona Roberts, oral history, 81-82. In Zona Roberts's recollection she said that the assistant superintendent who had made the "cheap diploma" comment met her outside before the school board meeting and said how proud he was of Ed. The change of attitude was a first sign of the institution's shift in favor of Ed graduating.

[245] Williams was appointed Dean of Men in 1959, but his title would change to Dean of Students in 1965. Arleigh Williams, "Recollections of the Dean of Students," an oral history conducted in 1985 by Herb Wiseman in *Disabled Persons' Independence Movement: The Formative Years, 1962-1977*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1987, 2.

[246] Zona Roberts, Ed Roberts, and Arleigh Williams all have slightly different recollections of this exact meeting. Zona's oral history states she, Ed, and the counselors from CSM went into Sproul Hall. Ed's oral history states that they met Williams in a hallway in Sproul Hall, but a comment from Zona in a footnote states they waited outside while a CSM counselor talked to Williams. Williams's oral history states the meeting was in his office. At the very least, it appears that Ed and Zona's first major interaction with a Berkeley official was an exchange with Arleigh Williams near or in Sproul Hall.

[247] Zona Roberts, oral history, 83; Arleigh Williams, oral history, 3-4.

[248] Henry Bruyn, "Director, Student Health Services, 1959-1972," an oral history conducted in 1994-1995 by Susan O Hara in UC Berkeley's Cowell Hospital Residence Program: Key Administrators and California Department of Rehabilitation Counselors, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 5-6; Zona Roberts, "Counselor for UC Berkeley's Physically Disabled Students Program and the Center for Independent Living, Mother of Ed Roberts," an oral history conducted in 1994-1995 by Susan O Hara, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 84-86; Timothy Pfaff,

academics, they could and should be able to attend UC Berkeley, and there was an entire wing going unused on the third floor of the hospital. CADR played an important role in establishing Cowell as a home for students with disabilities by assisting in recruitment and funding for refurbishing the wing to house students with disabilities. Ed Roberts would be the first student with a disability to live in Cowell Hospital and attend U.C. Berkeley, starting in 1962.[249]

Ed's acceptance at U.C. Berkeley and his residence at Cowell illustrates the double-sided nature of CADR and state institutions. Bruyn was a state official representing the public institution of the University of California and a medical expert who was crucial in helping Roberts receive a Berkeley education. When Zona and Ed went to visit Berkeley and Cowell, Bruyn gave them hope that an education for Ed was possible, saying:

> "You people who were in the polio epidemic are getting to be of college age now, and you haven't had a chance to go to college, and you really should have that chance. It's getting to be time to do that. This is a student-supported health center, so it can't cost the students any money for you to go to school here, or to live in Cowell. So we'd have to figure out a way for this to be paid for, but I think you could live in Cowell Hospital."

That was a transformative position and experience, according to Zona. Reflecting on that time, she said, "Just those few words from Henry Bruyn opened up a whole door for us that had been seemingly closed. How we were going to do this, or how we were going to get there, I didn't know. But with those words from Henry Bruyn, things began to happen."[250] State institutions certainly created some obstacles for those with disabilities seeking opportunities, but they also opened doors.

ii. John Hessler

Ed Roberts had been at Cowell for approximately six months when Bruyn received a call from a doctor in Martinez. The doctor said that he had a patient who would be a good candidate for the disability program in Berkeley. Bruyn said they did not have a disability program, but that there was a new student with disabilities and he was doing well at the university. The Martinez doctor asked Bruyn to come visit him in Contra Costa County Hospital.

When Bruyn arrived, the doctor took him into a room where there were four people with disabilities. Three were watching television, while the fourth was surrounded by books and listening to French broadcasts on the radio. Bruyn asked if that lone figure was Hessler, and the doctor confirmed that it was. Then and there, before Bruyn had even talked to Hessler, Bruyn told the doctor that Hessler was accepted based solely on that contrasting image, the singular individual surrounded by books and listening to French radio programs.[251]

Six years before Dr. Bruyn's visit, on May 6, 1957, John Hessler dove into Seven Mile Slough, just north of his home in Antioch, and his spinal cord snapped. He was swimming with friends, and it was only after a few moments of him being submerged in the water that his friends realized that something was wrong. After this injury Hessler lived in the county hospital ward before attending Diablo Valley College in Walnut Creek. He then transferred to U.C. Berkeley

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California Monthly, February 1985, retyped story by Minnesota's Governor's Council on Developmental Disabilities, 1.

[249] Bruyn, an oral history, 4-12; Henry Bruyn, "Disabled Students Live-In Program," memo as Director of Student Health Service, Cowell Memorial Hospital, no date, in Herbert Willsmore Papers, The Bancroft Library, BANC MSS 99/249c.

[250] Ed Roberts, oral history, 12-15; Zona Roberts, oral history, 84-85.

[251] Bruyn, oral history, 7-8.

and moved into Cowell Hospital as the second resident, after Ed Roberts. [252] These are just two experiences of Ed Roberts and John Hessler gaining opportunity through Cowell, but Henry Bruyn and other state actors like Eleanor Smith, a nurse who made students aware of Cowell at Berkeley helped aspiring students with disabilities gain access to U.C. Berkeley through Cowell.[253] Cowell was not considered to be an official "program" according to early residents; it was a place where students with physical disabilities lived, not part of an overarching organized institutional plan.[254] That would come later with the Physically Disabled Students' Program.

<u>iii. Patients or Students?</u>

The fundamental overarching question at the heart of the experience for those with disabilities living at Cowell was whether they were students or patients. This conflict would take a variety of forms, both explicit in clashes between counselors and residents, as well as more implicit forms, such as decorations and aesthetics of the living area—was it a hospital ward or a college dormitory? This conflict between residents with disabilities and the representatives of state institutions funding and operating the facility would shape the understanding of disability as a concept in the 1960s and 1970s.

Services provided at Cowell included a private room, three meals per day, custodial service, towels, maintenance of standard utilities, orderly and nursing care on a twenty-four hour basis, part time services of a registered nurse, services of a social worker aid, and all staff had to knock before entering an individual's private room and receive permission to enter.[255] Despite these services students would still consider the hospital wing to be their dorm.

The shift from hospital ward to dormitory floor could be seen in the aesthetic of Cowell's third floor. When Ed Roberts moved into the hospital in 1962, it was a sterile hospital wing. By 1970, it had converted into a dormitory straight out of the 1960s. Incense and marijuana smoke filled the air, with candles placed around creatively draped tie-dyed sheets and Indian bedspreads. A pool table and large dining table surrounded by free-flowing psychedelic painting schemes served as gathering spots. Afghan blankets and bookshelves were added to the rooms of students. As more students began to live at Cowell, parties became common and added to tension with the hospital staff.[256]

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[252] Lynn Kidder, "They fought disabilities and won," *Daily Ledger*, May 2, 1982, 1, 10-12, in Herbert Willsmore Papers, The Bancroft Library, BANC MSS 99/249c; "Rolling Quads, Project Director" memo to an unspecified Board of Directors, in Michael Fuss Papers, Bancroft Library, BANC MSS 99/146c.

[253] Cathrine Caulfield, oral history, 136; Herbert Willsmore, oral history, 158.

[254] James Donald, Student Resident at Cowell, 1967-1968, Attorney and Deputy Director of The California Department Of Rehabilitation, 1975-1982," an oral history conducted in 1998 by Kathryn Cowan in *University of California s Cowell Hospital Residence Program for Physically Disabled Students, 1962-1975: Catalyst for Berkeley's Independent Living Movement*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 77-80.

[255] "Cowell Rehabilitation Program," interdepartmental memo of Student Health Service in in Herbert Willsmore Papers, The Bancroft Library, BANC MSS 99/249c.

[256] Edna Brean, "Nurse Coordinator, Cowell Residence Program, 1969-1975," an oral history conducted in 1994-1995 by Susan O Hara in UC Berkeley's Cowell Hospital Residence Program: Key Administrators and California Department of Rehabilitation Counselors, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 40-42; Charles A. Grimes, "Attendant in the Cowell Residence Program, Wheelchair Technologist, and Participant/Observer of Berkeley's Disability Community, 1967- 1990s," an oral history conducted in 1998 by David Landes, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 57-63.

John and Ed would go out and explore Berkeley, but it was not always easy. One particularly rough time for Ed involved being hit by a flying basketball player and arrested by the Berkeley police—both in the same night. At a basketball game he was courtside because reporters wanted to get a picture of him with the basketball players. On a fast break one of the big Washington State players went racing down the court and dove for the ball which had been heading for Ed. The ball hit Ed, followed closely by the player, and Ed could have sworn his ankle was broken.

After the game Ed wanted to see some bluegrass music, and he did not want the painful ankle to get in the way. On his way to the bluegrass bar every crack in the sidewalk hurt his ankle, so when he arrived he started drinking until the pain went away. Both John and Ed realized they had to urinate, and while John had a leg bag, Ed needed to find a restroom. The restroom at the bar was not accessible, so he went outside with John. After relieving himself, he saw the light from a flashlight shined in his face and he heard a voice call "halt!" A police officer told him he was under arrest for public urination, but Ed told him the police station would need to have an iron lung or he would die. The officer called his sergeant and they told him he could go, but that they would report him to the university. Besides a few words with Henry Bruyn, there was no further action. But an inaccessible restroom at a bar and an inaccessible jail made for an eventful night out in Berkeley for the early Cowell residents.[257]

CADR also funded the education of those considered disabled, but the extent to which this funding was conditional on CADR rules and standards was contested by those with disabilities receiving it. Lucile Withington was the CADR counselor at Cowell from 1969-1971 and represented the interests of the state institution providing the funding. Ed Roberts was the main representative of the activists who argued that the funding should not be conditional on academic performance.

Roberts does not mince words when reflecting on his experience with Withington—he explicitly refers to her as "the villain," and that even on her best day "may not have been a very nice person." He took issue with the rules and standards she set as prerequisites for funding. She demanded that students provide her with their grades at the end of every semester in order to continue to receive support from CADR. Roberts was frustrated by these new rules and the threatening nature with which Withington implemented them, as she would threaten to revoke money if they were late providing her with their grades or did not provide them at all. Drawing on his past adversarial experiences with state institutions, Roberts tried to go above Withington's head to her supervisors, as well as reach out to the press to vilify her. He explicitly states that his effort to reach out to the press was an attempt to pressure Withington and CADR through vilification. Roberts and his fellow activists succeeded; Withington was transferred.[258]

As one might expect, Withington's recollection of this episode differs greatly from Roberts's. For her, it was a matter of providing funds to those who would appreciate them and take advantage of the opportunity, rather than arbitrarily depriving certain students of an education. According to her, Don Lorence and Larry Biscamp were two students receiving funding from CADR and they were not attending class or earning a GPA high enough to deserve the help from CADR. She saw the funding and the beds at Cowell as a zero-sum situation: every person there was taking the place of another individual considered disabled and therefore should fully utilize the educational experience and opportunities they had been provided through CADR

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[257] Ed Roberts, oral history, 21-23; Zona Roberts, oral history, 105.

[258] Ed Roberts, oral history, 35-39; Timothy Pfaff, *California Monthly*, February 1985, retyped story by Minnesota's Governor's Council on Developmental Disabilities, 3.

funding. If they were not going to attend class and earn a failing GPA, they should leave and make room for someone else who would better appreciate the opportunity.[259]

A San Francisco Chronicle article reporting on the clash between CADR and disabled Berkeley students certainly emphasized Withington's role in expelling them. The clash was framed as a personal and political issue rather than an academic one. Quotes from Roberts in the paper claimed they were being expelled for their long hair and activism, without any mention of academic performance other than to say they were "excellent students." Withington was unavailable for comment prior to the publication of the article.[260] After Withington returned from a month-long vacation she took issue with the article, specifically with the absence of any mention that the reason the students were being expelled was academic performance.[261]

Ed Roberts appeared to attribute malice when perhaps there was a genuine concern from Withington to make the most of the funding from CADR. In turn, Withington was perhaps too strict in her implementation of rules and standards on students. If they were not expelled or punished by the university, why was it in her power to impose different standards on the students than their peers who did not receive the funding? This adversarial exchange was less about which side was right and more about the extent to which state funding was conditional. Roberts and Withington were fundamentally arguing over whether and how CADR funding should be allocated. The question at the heart of their struggle appears to be whether state funding for vocational education was a right or a privilege. Roberts argued that it was a right and that Withington's intervention violated that right. Withington argued that funding was a privilege earned through high standards and achievement.

This early conflict between Roberts and Withington demonstrates the shades of gray in the relationship between CADR and the people it sought to help. Although CADR provided funding, it could also impose restrictions to which others who were not considered disabled were not subject. CADR was assisting in expanding capabilities and opportunities of those with disabilities, but the activists argued that the services and resources were simply establishing an even playing field rather than special treatment.

Perspectives from others who were not directly involved in the conflict reframe the adversarial relationship, and instead emphasize the ambiguous status of students with disabilities in Cowell. Were they patients or residents? For Dr. Henry Bruyn, CADR was vitally important in establishing Cowell through its funding for nurses, tuition, housing, and devices, as well as recruiting candidates for the program. However, he recognized the ambiguity of what exactly Cowell was: both a hospital and a residence. At an apartment or dorm the residents can come and go as they please, and have extensive autonomy over what they do and how they do it. If they wish to smoke, or invite people over, or arrive home late at night, that is their prerogative. A patient in a hospital does not have that same autonomy. While at the hospital, they are subject to the rules and control of medical professionals. These were college students who threw parties with alcohol and marijuana, and yet they were technically on the third floor of a hospital. Their attendants were also in the hospital wings of Cowell taking food from the kitchen upstairs to their clients, and the nurses took issue with scruffy tie-dye clothing—what Bruyn called

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[259] Lucile Withington, "Department of Rehabilitation Counselor, Cowell Residence Program, 1969-1971," an oral history conducted in 1994-1995 by Susan O' Hara in UC Berkeley's Cowell Hospital Residence Program: Key Administrators and California Department of Rehabilitation Counselors, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 85-87.

[260] "Students Accuse State Worker," *San Francisco Chronicle*, September 19, 1969, 2.

[261] Lucile Withington oral history, 88-90.

"goodwill chic".[262] Here was a fundamental difference in how the medical and public professionals saw the residents on the third floor of Cowell and how the residents saw themselves. The medical professionals viewed them as patients in need of care, and subject to the rules of nurses and CADR counselors, while the residents themselves saw their situation as students in a dorm like any other Berkeley student.[263] Bruyn saw the conflict between CADR and the students in the Withington-Roberts clash as an extension of this dynamic. Settling on an understanding of exactly what Cowell was and who had control of the third floor was a prolonged and difficult process. The compromise eventually worked out allowed the residents more autonomy than patients, although less than students.[264]

Cowell was not just a waystation in group consciousness,[265] it was a marked shift away from the medical model and toward the social model. The students with disabilities were advocating for accommodations that allowed them to pursue higher education within the same parameters as other students: in dorms, with autonomy over their living space, and academic standards left to the university to administer. CADR, as a California government institution, represented both the push and the pull the state had in this process by both providing the funding and facilities but then setting standards and conditions for those provisions. The clash between Roberts and Withington, as well as the more nuanced perspectives of Bruyn, all speak to this shift from a medical understanding to a social one.

Cowell was also where a sense of possibility developed through education and independence. Those with disabilities at this time saw education that was subsidized by state institutions like CADR as an opportunity to engage in their communities and live fulfilling lives with their disabilities. After becoming paralyzed in a car accident at the age of 19, Herbert Willsmore realized that he would need to use his mind to make a living if he could not do so with his body, saying "I knew that I couldn't make my living with my body any longer. So I thought, Well, this is an opportunity to use my brain." Eleanor Smith, a medical expert and nurse who specialized in rehabilitation, made Willsmore aware of the Cowell residence option, and a letter from Henry Bruyn started his process of enrollment at the university.[266] The emphasis on education and mental capacity was often cited as an avenue forward for opportunity after experiencing a physical impairment.[267]

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[262] Bruyn, oral history, 11-12.

[263] Karen Topp Goodwyn, "Department of Rehabilitation Counselor in Berkeley, 1972-1983," an oral history conducted in 1997-1998 by Mary Lou Breslin in UC Berkeley's Cowell Hospital Residence Program: Key Administrators and California Department of Rehabilitation Counselors, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 125.

[264] Henry Bruyn, oral history, 23-24; Zona Roberts, oral history, 106-107, 127.

[265] For a good analysis of the emergence of political activism and the development of the Rolling Quads, see Scot Danforth, "Becoming the Rolling Quads: Disability Politics at the University of California, Berkeley, in the 1960s," *History of Education Quarterly* 58 No. 4 (November 2018): 506-536.

[266] Herbert R. Willsmore, "Student Resident at Cowell, 1969-1970, Business Enterprises Manager at the Center for Independent Living, 1975-1977," an oral history conducted in 1996 and 1999 by Susan O'Hara in *University of California s Cowell Hospital Residence Program for Physically Disabled Students, 1962-1975: Catalyst for Berkeley's Independent Living Movement*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 156-159; "Autobiographical Summary," Herbert Willsmore, no date, 3, in "Herbert Willsmore Papers," The Bancroft Library, BANC MSS 99/249c.

[267] Lynn Kidder, "They fought disabilities and won," *Daily Ledger*, May 2, 1982, 11 (speaking of John Hessler's resolve to get an education after his paralysis); Catherine Campisi, "Leader in Higher Education and Disabled Student Services; Deputy Director and Director, California Department of Rehabilitation" an oral history conducted by Sharon Bonney in 2001, in *Rehabilitation, Higher Education, and Independent Living Services in California*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2004, 45; Brenda Premo,

The activism of students with disabilities within UC Berkeley was an explicit and direct origin of the Independent Living Movement. The students used the skills, knowledge, and cohesion they had learned to probe different avenues of developing organizations and institutions that would contribute to a wider impact on disability issues across the state and nation. John Hessler and Ed Roberts took their experience with the university administration and CADR at Cowell Hospital and used it to establish new organizations that would expand the services and accommodations developed while attending U.C. Berkeley. The first of these entities would be the Physically Disabled Students Program (PDSP) at the university.

C. The Physically Disabled Students Program

John Hessler founded the Physically Disabled Student Services at UC Berkeley during the 1960s. Services offered included financial aid, attendant referral and employment, and wheelchair maintenance. The development of group consciousness and resources at the university level expanded beyond the campus to civil society in the form of Centers for Independent Living. This expansion was possible due to federal funding through the Department of Education's Rehabilitation Services Administration.[268] Starting in 1969 Hessler led the movement to establish an organization that would implement the lessons of the Cowell experience.[269] The PDSP was set up in a building on Durant Avenue, a block away from the

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"Founding Director, Dayle McIntosh Center in Orange County; Member, National Council on Disability; Director, California Department of Rehabilitation" an oral history conducted by Kathy Cowan in 2001, in *Rehabilitation, Higher Education, and Independent Living Services in California*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2004, 79; Ed Roberts, oral history, 4-5, 29; Judith Heumann, "Pioneering Disability Rights Advocate and Leader in Disabled in Action, New York: Center for Independent Living, Berkeley; World Institute on Disability; and the US Department of Education 1960s-2000," an oral history conducted by Susan Brown, David Landes, Jonathan Young in 1998-2001, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2004, 49-50; Hale Zukas, "National Disability Activist: Architectural and Transit Accessibility, Personal Assistance Services," an oral history conducted in 1997 by Sharon Bonney in *Builders and Sustainers of the Independent Living Movement in Berkeley, Volume III*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 100-101; Ed Roberts called education his "path to freedom," in Timothy Pfaff, *California Monthly*, February 1985, retyped story by Minnesota's Governor's Council on Developmental Disabilities, 1.

[268] Hale Zukas, "National Disability Activist: Architectural and Transit Accessibility, Personal Assistance Services," an oral history conducted in 1997 by Sharon Bonney in *Builders and Sustainers of the Independent Living Movement in Berkeley, Volume III*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 118-119, 135-136; James Donald, Student Resident At Cowell, 1967-1968, Attorney and Deputy Director of The California Department Of Rehabilitation, 1975-1982," an oral history conducted in 1998 by Kathryn Cowan in *University of California s Cowell Hospital Residence Program for Physically Disabled Students, 1962-1975: Catalyst for Berkeley's Independent Living Movement*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 83; Cathrine Caulfield, "First Woman Student in the Cowell Program, 1968," an oral history conducted in 1996 by Susan O'Hara in *University of California s Cowell Hospital Residence Program for Physically Disabled Students, 1962-1975: Catalyst for Berkeley's Independent Living Movement*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 137. Judith Heumann, oral history, 249; Linda Perotti, "An Employee Perspective on the Early Days of the Cowell Residence Program, Physically Disabled Students' Program, and the Center for Independent Living," an oral history conducted by Kathy Cowan in 1998, Oral History Office, Bancroft Library, U.C. Berkeley, 2000, 121-125, 134; Ed Roberts, oral history, 45; Zona Roberts, oral history, 126; Betty H. Neely, "Recollections of the Director of Student Activities and Programs," an oral history conducted in 1984 by Herb Wiseman in *Disabled Persons' Independence Movement: The Formative Years, 1962-1977*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1987, 15.

[269] Lynn Kidder, "They fought disabilities and won," *Daily Ledger*, May 2, 1982, 1, 10-12, in Herbert Willsmore Papers, The Bancroft Library, BANC MSS 99/249c.

university campus above what was then and what is now the local favorite Top Dog. PDSP started primarily as an accommodating physical space where staff fixed devices, such as wheelchairs, and established an official attendant referral service for students with disabilities.[270] As important its role as counselor, attendant, and device services, it was a place where individuals with disabilities could meet and converse. Like Cowell, the PDSP office was a place where peers could network and support one another. It was loosely structured with few rules and flexible services, which could be a strength when addressing individuals with unique and diverse impairments.[271]

PDSP grew out of the Cowell experience and was needed for those who were seeking to leave the dormitory and navigate the university beyond the walls of the hospital. The political conflict with the university and the desire for more independence and autonomy led to its creation.[272] PDSP's main focus was centered on the individual with the disability and on infusing them with the autonomy and discretion over their own needs and capacity to integrate in the community. Hale Zukas, a Cowell resident and early disability rights activist, listed three primary functions for PDSP and what would later become the Center for Independent Living: First, "Those who know best the needs of disabled people and how to meet those needs are the disabled themselves." Second, "The needs of the disabled can be met most effectively by comprehensive programs which provide a variety of services." And third, "Disabled people should be integrated as fully as possible into their community."[273] After their experience at Cowell, Berkeley students wanted to implement a program that prioritized the individual. Herbert Willsmore, a former resident of Cowell, stated, "That's what Disabled Students' Program and the Center for Independent Living were all about: consumer input—the people that received the services actually having an effect over the design of the program and the evaluation of the program."[274]

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[270] Carol Fewell Billings, "Attendant and Observer in the Early Days of the Physically Disabled Students' Program and the Center for Independent Living, 1969-1977," an oral history conducted by Kathy Cowan in 1998, Oral History Office, Bancroft Library, U.C. Berkeley, 2000, 27; Cathrine Caulfield, oral history, 139; Karen Topp Goodwyn, oral history, 129, 136; Charles A. Grimes, "Attendant in the Cowell Residence Program, Wheelchair Technologist, and Participant/Observer of Berkeley's Disability Community, 1967- 1990s," an oral history conducted in 1998 by David Landes, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 72, 79; Linda Perotti, "An Employee Perspective on the Early Days of the Cowell Residence Program, Physically Disabled Students' Program, and the Center for Independent Living," an oral history conducted by Kathy Cowan in 1998, Oral History Office, Bancroft Library, U.C. Berkeley, 2000, 126-127, 131-132; Zona Roberts, oral history, 142. When Judith Heumann moved to Berkeley she would regularly have to go there for an accessible bathroom while on campus, see Judith Heumann, "Pioneering Disability Rights Advocate and Leader in Disabled in Action, New York: Center for Independent Living, Berkeley; World Institute on Disability; and the US Department of Education 1960s-2000," an oral history conducted by Susan Brown, David Landes, Jonathan Young in 1998-2001, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2004, 89, 238; Proposal for renewing Special Services' grant, fiscal year 1971, no credited author but signed by John Hessler, in Hale Zukas Papers, The Bancroft Library, U.C. Berkeley, BANC MSS 99/150c, Carton 2, 5, 10-11.

[271] Karen Topp Goodwyn, oral history, 129-130; Charles Grimes, oral history, 87; Proposal for renewing Special Services' grant, fiscal year 1971, no credited author but signed by John Hessler, in Hale Zukas Papers, The Bancroft Library, U.C. Berkeley, BANC MSS 99/150c, Carton 2, 10.

[272] Herbert Willsmore, "Autobiographical Summary" no date, in Herbert Willsmore Papers, The Bancroft Library, BANC MSS 99/249c.

[273] Edward V. Roberts, "California," in *Independent Living: Emerging Issues in Rehabilitation*, ed. Susan Pflueger, (Washington, D.C.: Institute for Research Utilization, 1977), 47, in Edward V. Roberts Papers, 1975-1998, The Bancroft Library, U.C. Berkeley, BANC MSS 99/34, Carton 1.

[274] Herbert Willsmore, oral history, 182.

In 1972, Larry Biscamp, Judy Taylor, and Herbert Willsmore wrote a paper with Charles Cole about the experience of people with disabilities working with rehabilitation counselors.[275] They emphasized the differing perspectives of the staff and residents of Cowell as a major disconnect that led to friction.[276] Their report also argued that organizations such as PDSP were meant to serve as a counterbalance to the power of CADR counselors. PDSP would provide those with disabilities with the instrument they needed to push against overbearing or paternalizing treatment from state-sponsored counselors.[277] They opposed condescending treatment from counselors who presumed a superior knowledge of the person's condition rather than listen to the individuals themselves. They wrote,

> "…among the more significant results of our inquiry was a more confident conviction that the best possibilities for what we are calling 'self actualization' of disabled persons lie in reforming and systematizing the now fragmented array of institutional situations with which they must contend. The absence of workable linkages between medical experiences and rehabilitative processes must, we think, be remedied. Most importantly, however, we urge a conversion of the rehabilitation process itself. We persist in our belief that the one-to-one relationship between a disabled client and the counselor who presumes superior knowledge of the world against whose norms the client's disability is measured is an unhealthy one. The experience of the Berkeley Special Services Project has demonstrated that an intellectually elite group of clients can bring about dramatic improvements in self-reliance and progress towards a style of rehabilitation acceptable to clients and [CADR] alike."[278]

PDSP also had controversies between individuals based on the dynamic of abled and disabled perspectives. While John Hessler was the director, there were other staff who were not considered disabled who could clash over which direction the PDSP should pursue. Further exacerbating this dynamic was the culture of cooperation and collective philosophy that eschewed hierarchical authority. Underlying the founding of the PDSP was a collective ethos based on decision-making by committee, but with respect to funding requirements and relations with the university, one individual—the director—was the representative authority speaking for the organization. The pay scale imposed by the university and the grant funding provided by federal and state entities assumed a hierarchical organization.[279]

Despite all of the services and accommodations provided by PDSP, student activists ultimately had one major goal: independent living.[280] Beyond attendant referrals, counseling, and wheelchair repair, PDSP had a philosophy of independence for its students with disabilities. A grant proposal in the early years of the program makes that clear; the proposal read:

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[275] Larry Biscamp, Judy Taylor, and Herbert Willsmore, with Charles Cole, "An Evaluation of Rehabilitation Counselor Training Programs from the Perspective of Disabled Clients," Working Paper, May 1972, Bancroft Library, pf HD7255.5 .B5 1972.

[276] Biscamp et al, "Evaluation of Rehabilitation Counselor Training Programs," 2.

[277] Biscamp et al, "Evaluation of Rehabilitation Counselor Training Programs," 3-4.

[278] Biscamp et al, "Evaluation of Rehabilitation Counselor Training Programs," 25-26.

[279] Charles Grimes, oral history, 81-82.

[280] Proposal for renewing Special Services' grant, fiscal year 1971, no credited author but signed by John Hessler, in Hale Zukas Papers, The Bancroft Library, U.C. Berkeley, BANC MSS 99/150c, Carton 2, 7, 14-15, 16; "Revisions to the Physically Disabled Student's Programs' Proposal for Special Services Funding Fiscal 1971," no author, no date, revisions in Hale Zukas Papers, The Bancroft Library, U.C. Berkeley, BANC MSS 99/150c, Carton 2, no page number.

> "The long term goals are many but they can be summed up in one word and that is – independence. All of our efforts lead to this goal. Academic success, physical stability, building self-confidence, encouraging students to handle their own financial affairs, hiring their own attendants, controlling their own lives, their own homes, all of these things that the program emphasizes have but one reason and that is to permit the disabled student to become an independent member of society…In the years to come it will no doubt be evaluated also by many members in the community who may for the first time realize that disabled individuals are human beings whose lives have value."[281]

PDSP was a shift from purely reactive development of accommodations and services by the university toward a clear concerted effort at providing a path to independence for students at U.C. Berkeley. During their time at Cowell, the students were responding to limitations and restrictions placed on them by hospital staff, the university, and CADR. At PDSP they were taking a more active and preemptive role in establishing methods and paths for independence.

Despite the clashes with government agencies and a push beyond paternal oversight, PDSP was still funded through federal grants and matching support from U.C. Berkeley. Both CADR and HEW provided vital funding for PDSP, and U.C. Berkeley worked closely with PDSP to create opportunities for students with disabilities. This funding came with requirements in terms of organizational structure and mandate. State funding institutions wanted to contact and communicate with individuals—not committees. This clashed with the communal, democratic hierarchy that PDSP had originally sought to emulate. The state funding imposed a hierarchy that put John Hessler, as director, in the unwanted position of representative of the power structure. It opened and widened a gap between the disabled and able-bodied staff members.

The relationship was not always adversarial; at times these state and federal entities were essential in promoting independence and opportunities for students with disabilities. The federal government was also a source of funding for PDSP. Just as with the establishment of Cowell as a residency for students with disabilities, the State of California and the federal government would be instrumental in establishing the institutions that would help people with disabilities. [282]

Overall, the impact of PDSP was profound, even lifesaving. A report by U.C. Berkeley's Disabled Students Program in February of 1987 surveyed former participants and showed how it had changed lives. Since 1962,[283] 155 students had participated in programs meant to aid students with disabilities, whether the Cowell program or PDSP.[284] The testimonials describe just how powerful the Cowell Program and PDSP had been in transforming the lives of students. A small sample includes: "It saved me from being institutionalized." "It was very valuable. You might say the Residence Program is what allowed me to live." "It allowed me to develop

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[281] Proposal for renewing Special Services' grant, fiscal year 1971, no credited author but signed by John Hessler, in Hale Zukas Papers, The Bancroft Library, U.C. Berkeley, BANC MSS 99/150c, Carton 2, quote on 14-15.

[282] Charles Grimes, oral history, 72, 81-84, 100; No author, no date, appears to be a draft of a grant proposal to the federal Department of Health, Education, and Welfare's Special Services Project, in Hale Zukas Papers, The Bancroft Library, U.C. Berkeley, BANC MSS 99/150c, Carton 2, 5-6; many of the grant proposals in Hale Zukas Papers, The Bancroft Library, U.C. Berkeley, BANC MSS 99/150c, Carton 2 target federal funding. See also, Zona Roberts, oral history, 143-144; Michael Fuss, "Attendant for Cowell Residents, Assistant Director of the Physically Disabled Students Program, 1966-1972," an oral history conducted by Kathy Cowan in 1997, Oral History Office, Bancroft Library, U.C. Berkeley, 2000, 62-63.

[283] The report seems to consider SHS's creation of the Cowell Residence Program as the "beginning" of PDSP, which is a mistake, PDSP was officially started eight years later.

[284] "Report on Employment Survey, Physically Disabled Students' Residence Program," Disabled Students' Program, U.C. Berkeley, report dated February, 1987, in in "Herbert Willsmore Papers," The Bancroft Library, BANC MSS 99/249c.

independently from my family…which led to working, home ownership, and a more fulfilling life." "I believe at the time, 1970, it was the most important single factor in changing my life to a more productive and meaningful one." "The residence program was very important to my gaining independence. My mother had done everything for me. I had never done anything on my own. I probably would still be living at home and not working if the Program had not existed." "Without it I would be dead."

These messages of gratitude and appreciation for the program illustrate its effectiveness. But its impact had been limited to students at U.C. Berkeley. The graduating students wanted to do more, and to do so they started the Center for Independent Living (CIL) to address the needs of the large community—not just students. The CIL would start out of a corner of PDSP's office on Durant Avenue.[285]

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[285] Hale Zukas, oral history, 118-119; Carol Fewell Billings, "Attendant and Observer in the Early Days of the Physically Disabled Students' Program and the Center for Independent Living, 1969-1977," an oral history conducted by Kathy Cowan in 1998, Oral History Office, Bancroft Library, U.C. Berkeley, 2000, 12; Michael Fuss, oral history, 84-87;

Chapter 4: "Advocrats": Advocates, Bureaucrats, and the Codification of Independent Living in California State Law

> "…I began with the Department of Rehab and it was my first job in a large bureaucracy. After about a month, I felt kind of like a bureaucrat. I thought 'What's happening?' What I really am is an 'advocrat', half advocate and half bureaucrat. That's what we need to be; we need to be advocates in every part of our systems. It works." Ed Roberts, 1979.[286]

The passage of Assembly Bill 204 into California state law on July 2, 1979, implemented the independent living ideas and concepts that had been developed at Cowell Hospital, the Physically Disabled Students' Program, and the Center for Independent Living.[287] It defined what independent living centers (ILCs) were in state law and it provided funding for them to operate and expand throughout the state. It was the union of state institutions and outside activism into a government funded nonprofit program that provided resources and services for those with disabilities.

Ed Roberts was appointed director of CADR on November 1, 1975, by Governor Jerry Brown Jr.[288] As director, he would help guide this statute through the legislature with the help of other Berkeley alumni and Cowell Residents like John Hessler, and Jim Donald, among others, while they also worked at the California Department of Rehabilitation. Yet AB 204 also had staunch allies in the legislature to author and advocate for the bill. Its legislative champion was Assemblyman Tom Bates. At U.C. Berkeley activists worked with important state actors like Henry Bruyn and Edna Brean, and Arleigh Williams, and they would do so again after leaving Berkeley to make an impact in the larger community outside the university and throughout the entire state. Disability activists would enter the halls of power and become agents of change within the system alongside important allies inside and outside of government.

This chapter analyzes how advocates moved into positions within state government and passed legislation codifying independent living centers throughout California. Disability advocates would take lessons learned throughout their time at Cowell and PDSP and apply them to California state governance. These advocates-turned-bureaucrats did not do it alone. Allies in the state legislature and at nonprofits proved to be crucial partners in passing the statute that would ultimately codify independent living in California state law. In this chapter, I trace the emergence of independent living as a concept at its embryonic state in student activism and how

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[286] "Draft of Ed's Speech in Dallas, Texas," April 25, 1979, page 9, in Edward V. Roberts Papers, 1975-1998, The Bancroft Library, U.C. Berkeley, BANC MSS 99/34, Carton 1.

[287] Assembly Bill Final History, Volume 1, California Legislature at Sacramento, 1979-80 Regular Session, 196; Office of the Governor Press Release, Barbara Metzger, Press Secretary, July 2, 1979, in California State Archives, Department of Rehabilitation, R204.004:20, (Box 3).

[288] Letter from Leslie F. James of Portland State University to Ed Roberts, with remarks from a meeting attended together, April 25, 1977; Edward V. Roberts, "A Founder's Perspective on Independent Living," World Institute on Disability, no periodical info, draft, both in Edward V. Roberts Papers, 1975-1998, The Bancroft Library, U.C. Berkeley, BANC MSS 99/34, Carton 1; Miriam Pawel, *The Browns of California: The Family Dynasty That Transformed a State and Shaped a Nation* (New York: Bloomsbury Publishing, 2018), 221.

it was ultimately converted into a state program sponsoring independent living centers up and down California, from Fresno to San Diego to Los Angeles to the Bay Area. Much has been written about Berkeley as a hotbed of disability activism, but the intricacies of passing this important legislation that provided fundamental services to individuals with disability has not been analyzed at an in-depth level.

This chapter makes multiple arguments pertaining to the operation of law. First, it shows how activists can implement change through advocacy. I argue that savvy activists can enter the halls of power and pull the necessary levers to achieve the change they seek. Second, I illustrate the importance of state actors in implementing that change. Throughout the disability rights movement activists were aided by crucial state actors; from doctors and nurses at Cowell Hospital to administrators at U.C. Berkeley to state legislators that would ultimately write the statute funding independent living, state officials were crucial contributors to the success of these efforts to redefine disability in law. Third, I emphasize that the law and its machinations are not abstract applications of words through agencies, but real flesh and blood people pushing and pulling through funding cuts, statutes dying in committees, expiring grants, and oppositional advocates to implement different conceptions of meaning—in this case the meaning of disability.

The chapter starts by analyzing the creation of the first independent living center, the Center for Independent Living in Berkeley (CIL). CIL's early days illustrate the important need of a steady funding source other than temporary and limited grants from the federal government and charities. It then shows how advocates-turned-bureaucrats began to work within the system alongside allies in the legislature to turn the philosophical concepts of independent living developed at Cowell and PDSP into state law.

I. The Students Leave Campus: The Center for Independent Living

Scholars have discussed Berkeley and the independent living movement as a major component of the disability rights movement.[289] While these important contributions have analyzed the independent living movement broadly, none have explored the impact this movement had on the relationship between the activists and state officials that culminated in the establishment of ILCs and their funding through state law.

The Center for Independent Living in Berkeley (CIL) was a direct product of the Cowell and PDSP experience. The seed of independent living philosophy planted at Cowell created two major branches, PDSP and CIL.[290] CIL was founded by Cowell residents, and it was the third manifestation of independent living concepts that had started at the university hospital and evolved into PDSP. Although it was grounded in the same principles, it was founded to address the needs of the wider community beyond the university's borders and student population.[291]

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[289] Samuel R. Bagenstos, *Law & the Contradictions of the Disability Rights Movement* (New Haven: Yale University Press, 2009), 15-17; Colin Barnes and Geof Mercer, *Exploring Disability: Second Edition* (Cambridge: Polity Press, 2010), 165-166; Edward D. Berkowitz, *Disabled Policy: America's Programs for the Handicapped* (New York: Cambridge University Press, 1987), 153-154, 202; Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Three Rivers Press, 1994), 41-55.

[290] Hale Zukas, "Part I: C.I.L. History," no date, 1, in Center for Independent Living Records, Bancroft Library at U.C. Berkeley, BANC MSS 2000/43c, Carton 5.

[291] Hale Zukas, "National Disability Activist: Architectural and Transit Accessibility, Personal Assistance Services," an oral history conducted in 1997 by Sharon Bonney in *Builders and Sustainers of the Independent Living Movement in Berkeley, Volume III*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 135-136.

Hale Zukas was a Berkeley student who was considered to be one of the more extreme radical activists in the DRM.[292] He did not live in Cowell, but he was active in protest movements, such as pouring asphalt to make unofficial curb ramps and he even insisted on being drafted during the Vietnam War despite his limited mobility in a wheelchair.[293] Zukas was instrumental in both the founding of PDSP and CIL, and he writes about what he considered to be a profound shift in understanding disability through the creation of these two institutions:

> "The approach envisioned in the proposed Physically Disabled Students' Program (PDSP) was a radical departure from past practice in the medical and rehabilitation fields. In contrast to the fragmentation which characterized the existing services, the PDSP would take a holistic, integrated approach by providing a comprehensive array of services in recognition of the fact that disabled people are likely to have a variety of needs, and functional independence will be hard to achieve unless all those needs are met. Self-evident though this may seem in hindsight such an approach had, to our knowledge, never been tried before."[294]

This is an additional layer to the original and creative breakthrough that was independent living. Both PDSP and CIL focused on the control of the organizations through a majority of board members with disabilities, and the autonomy of the individual by placing the individual's needs and discretion before that of the medical professional, but in addition to these concepts, CIL also provided comprehensive services. Rather than a piecemeal approach, independent living centers gave clients access to multiple different options at once, all in one place. It was an expansion of tangible assistance to live more fully and independently.

The first meeting to create CIL was on May 17, 1971, before it was even founded and incorporated. It featured eight disability advocates including John Hessler, Hale Zukas, and one of the students targeted by CADR counselor Lucile Withington in the attempt to pull funding at Cowell, Donald Lorence.[295] It essentially proclaimed the intent to create CIL, and the first board meeting would be later that same month on May 27, 1971. The proposed services it would provide were explicitly drawn from the PDSP proposal and the meeting itself would take place at PDSP offices.[296]

Much of the first board meeting was devoted to administrative issues, such as by-laws and nonprofit incorporation, but even that process was laden with intent to be innovative and experimental. Board members wanted to be a nonprofit because they wanted flexibility and a freedom from bureaucratic obstacles.[297] Aspirations of the disabled community also continued to

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[292] Jim Donald, Oral History in *University of California's Cowell Hospital Residence Program for Physically Disabled Students, 1962-1975: Catalyst for Berkeley's Independent Living Movement*, Regional History Office, The Bancroft Library, 85-86.

[293] Hale Zukas, oral history, 109-110, 121-122.

[294] Hale Zukas, "Part I: C.I.L. History," 3, emphasis in original.

[295] "First Meeting of the Potential Board of Directors," Center for Independent Living Records, Bancroft Library, U.C. Berkeley, BANC MSS 2000/43c, Carton 10; Hale Zukas, "Part I: C.I.L. History," 5; Hale Zukas, oral history, 118. Although Ed Roberts featured prominently in the DRM from Cowell to his directorship at CADR and beyond, he was not at these early meetings for CIL and John Hessler seemed to be the primary mover for both PDSP and CIL. Hale Zukas appears to disagree with the label of "co-founder of CIL" for Ed because of his absence from these first meetings. See, Hale Zukas, oral history, 119. Ed would not get involved in CIL until approximately two years after its founding.

[296] "First Meeting of the Potential Board of Directors," Center for Independent Living Records, Bancroft Library, U.C. Berkeley, BANC MSS 2000/43c, Carton 10. This appears to be an appendix to the first meeting.

[297] "First Meeting of the Potential Board of Directors," Center for Independent Living Records, Bancroft Library, U.C. Berkeley, BANC MSS 2000/43c, Carton 10.

be a concern. They were worried that community involvement would be difficult, because, "As we all know, most people are convinced that there is nothing they can really do to improve their lot. They have dreams but rarely do they know how to act effectively to realize their dreams."[298] Founders of CIL did not just want to provide tangible services, they wanted to galvanize the community and demonstrate that achievement of goals it thought were impossible were actually attainable.

The Articles of Incorporation for CIL stated that the first and primary purposes of founding CIL were "to establish, maintain and operate non-profit community service centers relating to, and for the purpose of improving, the physical, social and financial condition of physically disabled individuals." Two of the founding directors were the two students from whom Lucile Withington sought to withdraw funding while they were U.C. Berkeley Students at Cowell Hospital, Donald Lorence and Lawrence "Larry" Biscamp.[299]

From the beginning, funding was an issue. The main problem that plagued CIL was a lack of reliable resources to sustain the program and provide it with the requisite certainty of operations going forward. In its early days it mainly sought small-scale charity donations.[300] It was not until the federal Department of Health, Education, and Welfare's Rehabilitation Services Administration provided a grant of $50,311 on June 30, 1972, that CIL had actual substantial funding.[301] When that grant expired a year later in June 1973, Ed Roberts and John Hessler sought $15,000 of funding from both Vice Chancellor Robert Kerley of U.C. Berkeley and the City of Berkeley.[302] It was in 1973 that Ed Roberts would begin attending CIL board meetings.[303] This funding would last until the end of the year. More was provided by the San Francisco Foundation in December 1973 and Alameda County in March 1974.[304] On May 22, 1975, CIL would sign an agreement with CADR for funding of a new office on University Street in Berkeley and other expenditures. This would be CIL's first Innovation and Expansion grant, funded by the Rehabilitation Act of 1973, as amended in 1974, (the Rehabilitation Act hereafter). The act provided funding that was channeled through state agencies, in this case, CADR.[305]

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[298] "First Meeting of the Potential Board of Directors," Center for Independent Living Records, Bancroft Library, U.C. Berkeley, BANC MSS 2000/43c, Carton 10.

[299] "Articles of Incorporation of The Center for Independent Living, Inc.," in Center for Independent Living Records, BANC MSS 2000/43c, Carton 18.

[300] "Minutes of the Meeting of the Board of Directors on Monday, September 13, 1971," Center for Independent Living Records, Bancroft Library, U.C. Berkeley, BANC MSS 2000/43c, Carton 10; Hale Zukas, oral history, 119; Hale Zukas, "C.I.L. History," 6.

[301] "Project Development Grant, Program Title: Planning for a Community Rehabilitation Services Facility," Department of Health, Education, and Welfare, Rehabilitation Services Administration, Edward Newman, Commissioner, June 30, 1972, in Center for Independent Living Records, Bancroft Library, U.C. Berkeley, BANC MSS 2000/43c, Carton 10; Hale Zukas, oral history, 119.

[302] "Minutes CIL Board Meeting," July 30, 1973, in Center for Independent Living Records, Bancroft Library, U.C. Berkeley, BANC MSS 2000/43c, Carton 10. Hale Zukas credits Roberts and Hessler in his history of CIL, but the Board does not thank Roberts. It thanks Hessler, Herb Willsmore, Dave Knokel, and Dick Santos for their efforts in obtaining the funding.

[303] "Minutes Board Meeting," August 27, 1973; "Meeting of the Board of Directors of CIL," November 26, 1973; both in in Center for Independent Living Records, Bancroft Library, U.C. Berkeley, BANC MSS 2000/43c, Carton 10. Ed Roberts is occasionally mentioned in earlier board meetings as working on something related to disability or CIL, but did not appear regularly in the minutes as a guest or member. See, for example, Minutes of July 30, 1973.

[304] Hale Zukas, "C.I.L. History," 6-7.

[305] Agreement between the State of California Dept. of Rehabilitation and the Center for Independent Living, Inc." in Hale Zukas Papers, The Bancroft Library. University of California, Berkeley, (accessed online) https://oac.cdlib.org/view?docId=hb5w1004g3&brand=oac4&doc.view.

This funding pattern conveys two important aspects of disability activism and its capacity to meet the needs of the community. First, it again illustrates the importance of state support through officials providing the funding needed for the services, along with overhead and labor at the office itself. The federal Rehabilitation Services Administration, the public institution of U.C. Berkeley, and local government in the form of Alameda County and the City of Berkeley provided vital resources for the activists to implement their ideas and concepts of independent living. As with Dr. Henry Bruyn at U.C. Berkeley's Cowell Hospital, state representatives would be crucial in aiding activists with their advances in the disability rights movement.

However, a second and limiting aspect of this federal and local funding was that it was precarious and temporary—there was not a guaranteed stream of funding. For CIL not only to expand but just operate on a steady basis, it would need a more reliable source of funds. But it would not be until the passage of AB 204 that the State of California would become directly involved in funding independent living centers.

In order for the activists to establish dependable funding, they would need more state allies. One way of gaining support from state officials was to become state officials. Ed Roberts, John Hessler, and Jim Donald would all go to work at CADR when Ed Roberts was appointed director. But for them to achieve the goal of state legislative funding, they would need a state legislator to write the bill and introduce it to the floor. That legislator would be Tom Bates.

Tom Bates was also an alumnus of U.C. Berkeley before entering government. Born in San Diego in 1938, Bates developed an interest in law and government as early as the eighth grade, where he excelled in tests on constitutional governance and legislation.[306] He was accepted to U.C. Berkeley on a football scholarship, where he managed to play in the Rose Bowl game in 1959, while also playing on the rugby team.[307] After serving in the U.S. Army in Germany, Bates returned to Northern California and worked as a property manager and then salesman at Coldwell Banker.[308] He then worked as a partner with a friend buying property and building convenience stores and fast food buildings. It was during this time that his friend from U.C. Berkeley, Ken Meade, visited him at his house and asked for his help to fundraise for his upcoming state assembly campaign.[309] This was his gateway to California state politics.

For Ken Meade's first campaign in 1968 Bates primarily focused on raising money through his college alumni network. Even though Meade lost the election, Bates realized that campaigning and politics was his calling and he loved it, so he left commercial real estate to enter politics.[310] The transition was not easy—during Meade's successful election in 1970, Bates recalled,

> "I was working at this night and day—I weighed myself right after the campaign; I weighed 140 pounds (before the campaign I weighed 200 pounds). I was smoking three

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"Minutes, Regular Meeting of the CIL Board of Directors," March 28, 1977, in in Center for Independent Living Records, Bancroft Library, U.C. Berkeley, BANC MSS 2000/43c, Carton 10. There are no minutes in the records for 1976, but this record of board minutes shows an agenda item as "renewing I & E grant," suggesting they started receiving this funding in 1976.

[306] Oral history interview with Tom Bates: California State Assemblyman, 1977-1996, Alameda County Supervisor, 1973-1976," interviewed by Leah McGarrigle, Regional Oral History Office, University of California, Berkeley, BANC MSS 2004/274c, ii, 10, 29.

[307] Tom Bates, oral history, 30-40.

[308] Tom Bates, oral history, 55-75 (Army years), 77.

[309] Tom Bates, oral history, 49, 77-81.

[310] Tom Bates, oral history, 83-85, 96; David Donald Mulford, Oral History Interview, Conducted 1988 and 1989 by Timothy P. Fong and Ann Lage, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, for the California State Archives State Government Oral History Program, 81.

> packs of cigarettes a day. I was working from dawn till one in the morning, two in the morning, for this intense period of time…So I had everything: no job to go to, $18,000 in debt, physically a wreck, just unbelievably working night and day, but actually loving it, every minute of it, really."[311]

Bates's tireless work would pay off with a Meade victory, but the satisfaction was short-lived. Even before Meade took office, Bates became disillusioned when Meade went on trips to Hawaii and Jamaica paid for by lobbyists; and after Meade became a legislator Bates took issue with Meade's meals paid for by lobbyists, too.[312] Ultimately, Bates would feel that Meade had "betrayed all the things [they] were fighting for."[313] The former football and rugby player would get off the bench and into the game of politics, first as a member of the Alameda County Board of Supervisors, and then as a member of the State Assembly.

Bates would take this intense passion for politics into his own campaign and public service when he ran for the Alameda County Board of Supervisors and won easily after a door-to-door campaign. He represented Berkeley and North Oakland on the Board, and it was at this time he met Ed Roberts and became aware of the Center for Independent Living.[314] Bates would work with CIL to improve accessibility in county buildings.[315] Roberts went before the County Board to ask for grants that would fund CIL, so Bates started working to allocate county funds to the center as a supervisor. It was this initial connection that would lead to Roberts and Bates working together to pass AB 204 in 1979.[316]

II. The Need for AB 204

Prior to AB 204's passage in 1979 ILCs were primarily funded through two means, one from above the state level and one from below: federal grants and local governments. Both of these funding sources would be strained in the years and months leading up to July 1979. First, Proposition 13 reduced funding for local governments, and second, federal "Innovation and Expansion grants" (I & E grants) under the Rehabilitation Act of 1973, as amended in 1974 (the Rehabilitation Act) were set to expire after three years.

Proposition 13's passage on June 6, 1978, caused funding reductions and threats to operations for ILCs. Proposition 13 was a citizen initiative that limited both the initial and annual increases to the property tax rate while also mandating that two-thirds of voters approve special taxes from local governments.[317] This was a major blow to ILCs at the local level. Thomas Church, Executive Director of an ILC, wrote that his center saw a fifteen percent reduction in funding due to Proposition 13, and that continued reductions could cause a reduction in services.[318]

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[311] Tom Bates, oral history, 95-96.

[312] Tom Bates, oral history, 101, 103-104.

[313] Tom Bates, oral history, 107.

[314] Tom Bates, oral history, 109, 116-117, 122.

[315] "Regular Board Meeting," February 25, 1974, in Center for Independent Living Records, Bancroft Library, U.C. Berkeley, BANC MSS 2000/43c, Carton 10.

[316] Tom Bates, oral history, 127-128, 179.

[317] Mark Baldassare, Dean Bonner, Alyssa Dykman, and Lunna Lopes, "Proposition 13: 40 Years Later," Public Policy Institute of California, June 2018, https://www.ppic.org/publication/proposition-13-40-years-later/.

[318] CADR Memorandum from Roger Chapman to Jan Dell, February 9, 1979; in California State Archives, Department of Rehabilitation, R204.004:20.
Letter from Tom Bates to Pamela King, April 6, 1979; California State Archives, Tom Bates Papers, Bill Files, LP394:38.

Bates himself cited Proposition 13 as a major reason for AB 204. Speaking before the Assembly Resources Committee on March 6, 1979, he stated, "Up to this point, the centers have existed without receiving any special state funding. Private donations, city and county funds, and federal revenue sharing have been the main sources of funding for the centers—and, as you can imagine, the funds have never been abundant. Now, with the passage of Proposition 13, local government funds are drying up rapidly."[319]

AB 204 was not the first attempt by Bates to pass legislation providing state funding to independent living centers in California. Just a year before, Bates had authored AB 3051 which would have provided funding from the state, but the passage of Proposition 13 caused a funding earthquake, and AB 3051 died in the Assembly Ways and Means Committee.[320] In a bill analysis opposing AB 3051, the State Finance Department summarized AB 3051 as a bill that "would provide for State funding of existing independent living centers for the disabled and the development of new centers to provide services to disabled individuals to assist them in achieving social and economic independence. The bill also would require the Department of Rehabilitation to evaluate centers funded by this bill, and appropriates $3,000,000 for the program." The main opposition argument from the Finance Department was that independent living centers have been and should continue to be federally funded.[321] However, as advocates for AB 204 would make clear, there was a sunset on federal funding. Proposition 13 killed AB 3051 in committee in 1978, but that same proposition would be a major impetus and motivation for AB 204 a year later.

The second major effect on funding for ILCs leading up to the passage of AB 204 was the sunsetting of federal I & E grants under the Rehabilitation Act. I & E Grants illustrate the push and pull of federal influence. The Rehabilitation Act had tremendous value in opening the door of civil rights to people with disabilities. Section 504 of this act began tying federal funding to accessibility and accommodations for people with disabilities.[322] But in addition to that

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Letter from Thomas E. Church, Executive Director of Adult Independence Development Center, to Tom Bates, April 6, 1979, in California State Archives, Senate Health and Welfare Committee, Bill Files, LP207:67.

[319] Tom Bates, "Testimony Before Assembly Human Resources Committee," March 6, 1979, in California State Archives, Tom Bates Papers, Bill Files, LP394:38 [there is no name in the testimony, but it is found in the Tom Bates Papers, and the speaker refers to AB 204 as "my bill," suggesting it is Bates, the author of AB 204; emphasis in original].

[320] Bill Analysis from Ed Roberts as Director of CADR, January 19, 1979; Bill Report from Ed Roberts as Director of CADR, May 31, 1979; Memorandum on AB 204 provided to Chairman of the Assembly Human Resources Committee Richard Alatorre, hearing date March 6, 1979 (also in Bates papers, see below); all located in California State Archives – Department of Rehabilitation, R204.004:20, (Box 3). See also, Draft of Letter to Assembly Colleagues from Tom Bates regarding Independent Living Centers (AB 204), January 4, 1979; Draft of Letter to Members of the Senate and Assembly from Tom Bates regarding Independent Living Centers (AB 204), January 4, 1979; Letter from Tom Bates to Leo Mouton, January 17, 1979; Senate Committee of Health and Welfare, Staff Analysis of Assembly Bill 204 (Bates) (As Amended May 3, 1979); Assembly Office of Research, "Unfinished Business: Concurrence Amendments," no date (appears to be after Assembly vote on May 10, 1979 and before Senate vote on June 22, 1979), "Assembly Third Reading AB 204 (Bates) As Amended: May 3, 1979," by Assembly Office of Research, May 10, 1979; all located in California State Archives, Tom Bates Papers, Bill Files, LP394:38.

"Quarterly Bill Status Report," CADR, October 16, 1978, in Center for Independent Living Records, Bancroft Library at U.C. Berkeley, BANC MSS 2000/43c, Carton 5.

[321] Bill Analysis, AB 3051, California State Department of Finance, no date, in California State Archives, Department of Rehabilitation, R204.004:20, (Box 3).

[322] Edward D. Berkowitz, *Disabled Policy: America's Programs for the Handicapped* (New York: Cambridge University Press, 1987), 212-215; Robert L. Burgdorf Jr., Substantially Limited Protection from Disability Discrimination: The Special Treatment Model and Misconstructions of the Definition of Disability, 42 Villanova

provision, it also authorized funding for states to provide nonprofits working to promote opportunities for those with disabilities. These grants were meant to "initiate or expand such services to individuals with the most severe handicaps, or of special programs…to classes of handicapped individuals who have unusual and difficult problems in connection with their rehabilitation, particularly handicapped individuals who are poor…"[323] When Ed Roberts became Director of CADR he used these grants to set up nine additional ILCs.[324]

These grants not only funded projects like independent living centers, but also expanded rehabilitation mandates to include the most severely impaired individuals. However, they were set to expire three years after the first funding allocation, so ILCs only had three years of federal funding before they needed to become self-sustaining or find another source of funding.[325] Many California ILCs were in danger of shutting down due to this expiration of funding in the lead up to AB 204 in 1979.

In February of 1979, thirteen ILCs in California received $831,200 of federal funding from I & E grants; and at least eight of those centers were in their third and final year of funding. Many ILCs that received I & E grants through the Rehabilitation Act would lose that funding between June 30 and December 30 of 1979, and at least five would likely shut down after the I & E grants expired.[326] CADR recognized that this was an existential threat to ILCs throughout California toward the end of 1978, and began studying solutions to the reduction in funding, which included legislative action.[327]

Local governments and the nonprofits themselves highlighted the gravity of reduced funding as I & E grants began to expire.[328] Douglas C. Broten, Director of the California Association of the Physically Handicapped Service Center in Fresno, wrote to Thomas Bates about AB 204, stating that their I & E grant would expire on November 14, 1979, and at the time

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Law Review 409 (1997), 414-417; Nielsen, *A Disability History of the United States*, 165-167; Ruth O'Brien, "From a Doctor's to a Judge's Gaze: Epistemic Communities and the History of Disability Rights Policy in the Workplace," 35 *Polity*, 328-329; Richard K. Scotch, *From Good Will to Civil Rights: Transforming Federal Disability Policy*, (Philadelphia: Temple University Press, 2001), *passim*.

[323] 29 U.S.C. § 741 (Supp. IV, 1974).

[324] Ed Roberts Testimony on the Center for Independent Living, Subcommittee on House of Representatives, Subcommittee on Select Education Hearing, January 5, 1978, in in Edward V. Roberts Papers, 1975-1998, The Bancroft Library, U.C. Berkeley, BANC MSS 99/34, Carton 1.

[325] 29 U.S.C. §§ 740 and 741 (Supp. IV, 1974).

[326] "Comments on Your A.B. 204 Analysis," CADR Memorandum from Jim Wigton to Jan Dell, January 18, 1979; Bill Analysis of AB 204 (Bates), Health and Welfare Agency, Department of Rehabilitation, Director Edward V. Roberts, January 19, 1979; "Back Up for AB 204 (Bates)", CADR Memorandum from Roger Chapman to Jan Dell, February 9, 1979; all in California State Archives, Department of Rehabilitation, R204.004:20, (Box 3). See also, Senate Committee of Health and Welfare, Staff Analysis of Assembly Bill 204 (Bates) (As Amended May 3, 1979); Assembly Office of Research, "Unfinished Business: Concurrence Amendments" AB 204 (Bates); Legislative Analyst (no name) "Analysis of Assembly Bill No. 204 (Bates) As Amended in Senate May 31, 1979, 1979-1980 Session," June, 1979; Bill Analysis of AB 204 (Bates), California Department of Finance, 1979; in California State Archives – Tom Bates Papers – Bill Files – LP394:38. Exact projections differed, but the sources agree that at least nine were in their last year of funding and at least five would likely fail without additional funding.

[327] CADR Memorandum from Robert W. Chapman to Resources Specialists, Subject: ILP Short-Term Survival, October 18, 1978; CADR Memorandum from Robert W. Chapman to Phil Lades, Subject: Independent Living Programs, October 18, 1978; in Center for Independent Living Records, Bancroft Library at U.C. Berkeley, BANC MSS 2000/43c, Carton 5.

[328] Letter from Norman D. Boyer, Legislative Representative of the City Council of the City of Los Angeles, to Assemblyman Tom Bates, June 5, 1979; Letter from Douglas C. Broten, Director of The Fresno County Chapter of the California Association of the Physically Handicapped, to Tom Bates, March 30, 1979; in California State Archives, Tom Bates Papers, Bill Files, LP394:38.

of writing they had no funding beyond that date. He went on to state, "at the conclusion of the I & E Grant we might have to close our doors."[329] From internal government memorandums to letters of nonprofit directors, it is clear that the looming reduction in federal funding through these grants was a major impetus for the passage of AB 204.

In addition to providing funding through I & E grants, the Rehabilitation Act also provided AB 204 with its the definition for "handicapped individual" under §706. A "disabled individual," was "defined pursuant to the Federal Vocational Rehabilitation Act of 1973 (Section 706 of Title 29 of the United States Code), as amended in 1974."[330] For the subchapters concerning rehabilitation funding related to AB 204, this section defined such an individual as anyone "who (A) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment and (B) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services…"[331] The intellectual exchange between federal and state governments continued, this time with the federal government providing California with explicit language for this statute's definition of "disabled individual."

With two major sources of funding expiring, proponents of independent living needed a solution that would provide a firmer funding source for ILCs across the state. Activists at CIL and other ILCs wrote to state legislators and advocated for state funding. With Roberts, Hessler, and Donald at CADR, and Bates in the State Assembly, actors inside government were positioned to provide that funding through AB 204.

III. The Passage of AB 204

Proponents of AB 204 were bolstered by a letter-writing campaign from ILCs and other interested organizations throughout the state. During the first six months of 1979 impacted

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[329] Letter from Douglas C. Broten, Director of The Fresno County Chapter of the California Association of the Physically Handicapped, to Tom Bates, March 30, 1979, in California State Archives, Tom Bates Papers, Bill Files, LP394:38

[330] Chapter 191, *Statutes of California*, 421.

[331] 29 U.S.C. § 706 (Supp. IV, 1974). Two notes: first, the federal act used "handicapped" individual while California's AB 204 used "disabled." The exact reason for this is unknown, but Roberts may have influenced the terminology, as Bates stated in his oral history that Roberts preferred "disabled" to "handicapped." Tom Bates, oral history, 498.

The more famous definition relevant for other subchapters (IV and V) is the definition that would eventually be adopted in the Americans with Disabilities Act of 1990 (ADA). For a good discussion of that three-pronged definition and its implementation in the ADA, see, Robert L. Burgdorf Jr., "Substantially Limited Protection from Disability Discrimination: The Special Treatment Model and Misconstructions of the Definition of Disability," 42 Villanova Law Review 409 (1997).

organizations wrote to state assembly members[332] and senators.[333] Beyond support and appreciation, they emphasized three major points. First, they argued that this was a cost-saving measure for the state by providing the means for individuals with disabilities to achieve employment and no longer use welfare payments. Douglas Martin, Executive Director of

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[332] Letter from Peter Leech to Assemblyman Richard Alatorre, January 19, 1979; Letter from Mary M. Rodocker, Training Supervisor, Sex and Disability Training Project at U.C. San Francisco, to Thomas Bates, February 5, 1979; Letter from Hubert J. Sellner, Legislative Chairman of the California Association of the Deaf, to Tom Bates, February 8, 1979; Letter from Carlos L. Engle, Sr., volunteer in Azusa, CA, to Thomas Bates, February 9, 1979; Letter from Robert G. Dicus, Chairman of the Board of Trustees of Amyotrophic Lateral Sclerosis Society of America, to Thomas Bates, February 9, 1979; Letter from Robert G. Dicus, Executive Director of Western Independent Living Foundation, to Thomas Bates, February 9, 1979; Letter from Louis Hunt, Director of Development at Behavioral Sciences Institute Foundation, to Thomas Bates, February 14, 1979; Letter from Paul Slawson of the California Psychiatric Association to Tom Bates, February 15, 1979; Letter from Jacob S. Blass, Director of Patient Services at National Multiple Sclerosis Society, Southern California Chapter, to Tom Bates, March 1, 1979; Letter from Henry N. Henscheid, Director of Advocacy for Easter Seal Society (San Francisco) to Tom Bates, March 2, 1979; Letter from Douglas Martin, Executive Director of Westside Community For Independent Living, to Thomas Bates, March 2, 1979; Letter from Douglas C. Broten, Director of The Fresno County Chapter of the California Association of the Physically Handicapped, to Tom Bates, March 9, 1979; Letter from Douglas C. Broten, Director of The Fresno County Chapter of the California Association of the Physically Handicapped, to Tom Bates, March 30, 1979; Letter from Thomas E. Church, Executive Director of Adult Independence Development Center, to Tom Bates, April 6, 1979; Letter from Wilda M. Flower, President of the California Speech and Hearing Association, to Tom Bates, April 6, 1979; Letter from Ernest Faulkner Jr., Executive Director of Community Rehabilitation Industries, to Thomas Bates, April 9, 1979; Letter from Everett M. Jess, Director of San Diego Service Center for the Blind to Thomas H. Bates, April 9, 1979; Letter from Jacob S. Blass, Director of Patient Services, Southern California Chapter of the National Multiple Sclerosis Society, to Members, Assembly Ways & Means Committee, no exact date but draft sent with another letter on April 11, 1979; Letter from Nick Hambrick of Rolling Start: Independence in Daily Living, to Tom Bates, April 11, 1979; Letter from Carlos L. Engle, Sr., volunteer in Azusa, CA, to Thomas Bates, April 15, 1979; Letter from Irving R. Stone as Chairman of the Organization of Area Boards for Developmental Disabilities to Assemblyman Tom Bates, May 25, 1979; Letter from Norman D. Boyer, Legislative Representative of the City Council of the City of Los Angeles, to Assemblyman Tom Bates, June 5, 1979; all in California State Archives, Tom Bates Papers, Bill Files, LP394:38**.**
An Open Letter from the Center for Independent Living (Berkeley) to Members of the Ways and Means Committee, April 24, 1979, in California State Archives, Department of Rehabilitation, R204.004:20, (Box 3).

[333] Letter from Jane A. Lefferdink, Executive Director of United Cerebral Palsy Association of Santa Clara/San Mateo Counties to Tom Bates, April 3, 1979, (to Tom Bates but stating letters of support for AB 204 have gone to state senators); Letter from Annie Grdjan, President of the Board of Directors for Center for Living Independently in Pasadena, to State Senator Diane Watson, May 18, 1979; Letter from Annette Rubino, Co-director of Independent Living Resource Center in Santa Barbara, California, to State Senator Omar Rains, May 31, 1979; Letter from Annette Rubino, Co-director of Independent Living Resource Center in Santa Barbara, California, to State Senator Robert Nimmo, May 31, 1979; Letter draft, Center for Independent Living, marked "This is going to everyone in the senate who hasn't voted on the bill yet," June 13, 1979; Letter from Dorothy E. Labudde, President of the California Speech—Language—Hearing Association, to State Senators, June 18, 1979; Letter from F.A. Caligiuri, Executive Director of The California Association of the Deaf to state senators, June 20, 1979; all in California State Archives, Tom Bates Papers, Bill Files, LP394:38. See also, Letter from Douglas C. Broten, Director of CAPH Service Center, to Senator John Garamendi, March 14, 1979; Letter from Irving R. Stone, Chairperson of the Developmental Disabilities Organization of Area Boards, to John Garamendi, Chairman of the Senate Health and Welfare Committee, May 14, 1979 ; Letter from William Tainter, Executive Director of Community Service Center for the Disabled, to John Garamendi, Chairman of the Senate Health and Welfare Committee, May 14, 1979; Letter from Dana Lamon, Executive Director of Disabled Resources, to Members of the Senate Health and Welfare Committee, May 16, 1979; Letter from Geno M. Vescovi and Brenda Premo, Dayle McIntosh Center, to Senator John Garamendi, May 16, 1979; Letter from John H. King, Executive Director of United Cerebral Palsy Association of San Francisco, to Senator John Garamendi, May 21, 1979; Letter from Ralph S. Griffin, Chairperson of Area Board V Developmental Disabilities, to John Garamendi, Chairman of the Senate Health and Welfare Committee, May 21, 1979; in California State Archives, Senate Health and Welfare Committee, Bill Files, LP207:67.

Westside Community For Independent Living, wrote, "…enactment of [AB 204] would be highly cost-effective. By helping existing independent living programs and stimulating the development of new ilp's (sic), tens of thousands of disabled people could continue to live in their communities, saving the state the expense of institutionalization."[334] Mary Rodocker of U.C. San Francisco's Department of Psychiatry made a similar point, writing, "The results of these services, if degrees of independence can be measured in dollars, are cost effective."[335] Framing AB 204 as a cost-saving mechanism was a crucial component of the advocacy for its passage.

Second, they pointed out that without this additional funding, their centers would either need to reduce services or shut down entirely. F.A. Caligiuri of the California Association of the Deaf wrote, "Without the funding provided by AB 204, over half of these [ILCs] in the State will close."[336] The ILCs were facing an existential funding threat in the wake of Proposition 13 and the sunsetting I & E Grants. AB 204 would not just boost services for those with disabilities, it was a lifeline after a dramatic reduction in funding.

Third, they put the passage of the bill in existential terms for those living with disabilities. It was a threat to their capacity to exist in communities and have meaningful lives. Phil Draper and Judy Heumann of CIL at Berkeley wrote letters to state senators and Governor Brown (the language was the same in each) stating, "Within the next few days you must make a very important decision. You must decide whether to enable persons with disabilities to live as independent, self-supporting, tax-paying citizens. You must decide whether de-institutionalization of disable (sic) individuals is a priority in California." They included the story of a client who had been a post-polio quadriplegic since the age of three. His parents could no longer care for him after he reached the age of twelve, so he moved among various medical facilities, only seeing staff and his own immediate family. With CIL's help, the client had been able to move into a college dormitory at the age of twenty-seven. He would be moving into his own apartment with continued assistance from CIL. They wrote, "During his institutionalized years, [the client] rarely went outside and never saw the sun set. Now his horizons are far beyond the walls of a state institution as he looks forward to completing his college education."[337]

Support for AB 204 also came from inside state agencies and local government.[338] To no one's surprise, arguably the fiercest advocate for the passage of AB 204 was CADR director Ed

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[334] Letter from Douglas Martin, Executive Director of Westside Community For Independent Living, to Thomas Bates, March 2, 1979, in California State Archives, Tom Bates Papers, Bill Files, LP394:38.

[335] Letter from Mary M. Rodocker, Training Supervisor, Sex and Disability Training Project at U.C. San Francisco, to Thomas Bates, February 5, 1979, in California State Archives, Tom Bates Papers, Bill Files, LP394:38.

[336] Letter from F.A. Caligiuri, Executive Director of The California Association of the Deaf to state senators, June 20, 1979; in California State Archives, Tom Bates Papers, Bill Files, LP394:38.

[337] Letter draft, Center for Independent Living, marked "This is going to everyone in the senate who hasn't voted on the bill yet," June 13, 1979; Letter from Phil Draper and Judy Heumann of Center for Independent Living to Governor Jerry Brown, June 26, 1979; both in California State Archives, Tom Bates Papers, Bill Files, LP394:38.

[338] Memorandum from Roger Chapman to Jan Dell promoting AB 204, Jan 10, 1979; Letter from Harry N. Greenblatt, Chief of Research Section of CADR, to Ted Lasher, Assembly Human Resources Committee, March 5, 1979; Memorandum from Richard B. Spohn, Director, and Steve Fishbein, Legislative Coordinator of the Legislative Office, to Diana Dooley, Legislative Secretary in the Governor's Office, April 27, 1979; Memorandum "Bi-Weekly Report" from Jan Dell, Legislative Coordinator of CADR to James Donald, Deputy Director for Legal Affairs, CADR, May 4, 1979; Letter from Tom Bradley, Mayor of Los Angeles, to Leo McCarthy, Speaker of the Assembly, May 8, 1979; all in California State Archives, Department of Rehabilitation, R204.004:20, (Box 3).

Roberts himself.[339] Roberts took the lessons from Cowell, PDSP, and CIL into California state government "advocracy" and devoted them to winning state funding for ILCs. While the exact date and time that the position of the "social model" became viable is unclear in the disability scholarship,[340] it was definitely instrumentalized by Ed Roberts on May 2, 1977, in his efforts to establish ILCs as CADR director—the same year as Lynn Thompson's suicide. In an internal CADR document Roberts advanced social model concepts to justify the need for ILCs and the need for state funding. The exact language of his position is a striking in its affirmation of the social model for independent living and is worth quoting at length. He writes,

> "We have all seen over and over again that the severity of the disability, whether it be mental, physical or addictive, is not the overwhelmingly critical factor that prevents an individual from functioning independently in society… We know now that it is not the severity of the disability that prevents an individual from integrating into society. The major factors are the attitudinal barriers shared by society and by disabled persons themselves, the feelings of devaluation, the isolation, the lack of social skills and the scarcity of role models. It is our system of institutionalization and our welfare programs that penalize those who try to find jobs or to live on their own. And finally, it is the lack of basic support services in the community and the existence of mobility barriers."[341]

Roberts could have been writing explicitly about Lynn Thompson, especially in his reprobation of institutionalization and welfare programs that served as obstacles to independence. He explicitly placed the onus on environmental and attitudinal barriers as opposed to individual impairments. ILCs were a way of ameliorating these conditions to provide more opportunities for those with disabilities.

In December of 1977, Roberts characterized independent living as "the civil rights movement of millions of Americans with disabilities. It is the wave of protests against segregation and discrimination and an affirmation of the right and ability to share fully in the responsibilities and joys of our society." He again used language of an early version of the social model of disability to advance an argument for independent living's role in rehabilitation, writing that, "The problem we now face is how to make changes in our environment so that these

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[339] Letter from Ed Roberts to Richard Alatorre, Chairman of the Assembly Human Resources Committee, February 28, 1979, [date crossed out]; Letter from Ed Roberts to Chairman of the Assembly Human Resources Committee Richard Alatorre, March 6, 1979; in California State Archives, Department of Rehabilitation, R204.004:20, (Box 3).

[340] Part of this lack of clarity stems from what one might consider to be a clear manifestation of the social model. For example, an English disability scholar cites the founding principles of the Union of the Physically Impaired Against Segregation (UPIAS) in 1976 as the "starting point" for the social model. Michael Oliver, *Understanding Disability: From Theory to Practice, Second Edition*, (New York: Palgrave Macmillan, 2009), 6, 42-43. However, Het Dorp is a town in the Netherlands built for those with physical disabilities in 1964. It physically removed barriers and obstacles to allow those with impairments to live unobstructed. See Irving Kenneth Zola, *Missing Pieces: A Chronicle of Living With a Disability* (Philadelphia: Temple University Press, 1982 [2004]), 12, *passim*. Does the construction of that town constitute a manifestation of the social model? What about the principles of PDSP and CIL? These are debatable, but it can probably be said that the social model began to emerge in the 1960s and 1970s.

[341] Ed Roberts, Department of Rehabilitation Report, "The Case for Independent Living" May 2, 1977 (quote); he would express similar opprobrium against attitudinal barriers in Edward V. Roberts, "The Courage to Take Risks," *The Unesco Courier*, January 1981; Edward V. Roberts, "Disabled Peoples' International: A Symbol of Determination," in *Rehabilitation/WORLD*, Summer/Fall 1982; in Edward V. Roberts Papers, 1975-1998, The Bancroft Library, U.C. Berkeley, BANC MSS 99/34, Carton 1.

persons can complete the rehabilitation process and become actively participating and valued members of our communities."[342]

If the first tenet of Roberts's conception of independent living was the removal and destruction of barriers, a second tenet was the importance of individual agency. The centrality of individual choice was the "ability to actively participate in society—to work, have a home, raise a family, and generally share in the joys and responsibilities of community life. 'Independent living' means freedom from isolation or from the institution; it means the ability to choose where to live and how; it means the individual's ability to carry out activities of daily living that non-disabled often take for granted." Individual choice and agency were of crucial importance.[343] In 1981, Roberts would write, "We are entering a new era and are finally recognizing that people with disabilities are not objects of charity. They are people with rights: specifically, the right to develop to their fullest potential, whatever that might be. A new philosophy is taking hold, one that acknowledges each person's potential; we are realizing that we can't write anyone off, and that we can't define people's limits for them. People have to define their own limits."[344]

A third major element in Roberts's argument for ILCs was the importance of integration rather than segregation. He remarked, "It seems to me that segregation in and of itself has been one of the most devastating things that disabled people could have experienced. Not so much the fact that people have been pushed aside in our society, but the fact that people have been systematically segregated. It wasn't done by evil people. I think it was done in a meaningful way."[345] Segregation was a two-fold impediment for individuals with disabilities. First, it prevented a proper socialization of the individual into their community through a deprivation of skills that could have been developed through social interaction. Second, it negatively impacted the perspectives of those in the wider population for people with disabilities, making them scarce and unseen in institutions rather than immersed in the community.[346]

In a March 6, 1979, letter to Richard Alatorre, Chairman of the Assembly Human Resources Committee that deliberated over AB 204, Ed Roberts also stressed the economic efficiency of the bill, writing that ILCs "can be cost beneficial not only by enabling disabled persons to live outside of institutionalized settings but by enabling more disabled persons to become job ready, taxpaying citizens." He urged Alatorre's support by stating that ILCs "focus on integration," and provided "services needed to enable persons with disabilities to function

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[342] Edward V. Roberts, "Foreword," in "Independent Living: Emerging Issues in Rehabilitation" eds. Susan Pflueger, for the Institute for Research Utilization, December 1977, ii, in Edward V. Roberts Papers, 1975-1998, The Bancroft Library, U.C. Berkeley, BANC MSS 99/34, Carton 1.

[343] Edward V. Roberts, Director, CADR, and Susan Stoddard, Senior Analyst, Berkeley Planning Associates, "Independent Living: Concept and Programs," draft, prepared for *American Rehabilitation*, April 5, 1978, in Edward V. Roberts Papers, 1975-1998, The Bancroft Library, U.C. Berkeley, BANC MSS 99/34, Carton 1.

[344] Ed Roberts, "Statement by Ed Roberts, Director, California Department of Rehabilitation for the Geneva Committee for the International Year of the Disabled," in *A New Look for New Perspectives*, July 8, 1981, in Edward V. Roberts Papers, 1975-1998, The Bancroft Library, U.C. Berkeley, BANC MSS 99/34, Carton 1.

[345] Letter from Leslie F. James of Portland State University to Ed Roberts, with remarks from a meeting attended together, April 25, 1977, in Edward V. Roberts Papers, 1975-1998, The Bancroft Library, U.C. Berkeley, BANC MSS 99/34, Carton 1.

[346] Ed Roberts, speech draft, March 25, 1977, no exact location/context provided; Ed Roberts, speech draft, California Behavior Analysis Conference, March 30, 1977; in Edward V. Roberts Papers, 1975-1998, The Bancroft Library, U.C. Berkeley, BANC MSS 99/34, Carton 1.

independently." Yet he still recognized the importance of cost analysis when closing the letter by emphasizing the fiscal benefits of the bill.[347]

For Roberts, independent living centers were products of a government-funded nonprofit program, but also the instantiation of a paradigm shift in thinking about disability. They altered the meaning of what it meant to be disabled and shifted in the burden of responsibility for engagement and action. They were the manifestation of a move away from a pure individualistic medical model and toward the social model's placement of responsibility on social remedies as opposed to individual ones.

AB 204 was introduced in the State Assembly on January 3, 1979, and referred to the Committee on Human Resources the next day.[348] It passed through the Committee on Human Resources unanimously (8-0) and moved to the Committee on Ways and Means.[349] In the Assembly Ways and Means Committee the total sum allocated dropped from three million dollars to two million dollars. There is no discernible reason for this given in the committee's files related to the bill, but its fifth amendment strikes the allocation of three million dollars and replaces it with "The sum of two million dollars ($2,000,000)."[350] After the committee reduced the funding by one million dollars, the bill passed through the committee unanimously (21-0).[351] In May 1979 it passed the Assembly unanimously (77-0) and moved to the Senate.

AB 204 passed through the Senate Health and Welfare Committee unanimously and then went to the Senate Finance Committee.[352] The Finance Committee was the first time AB 204 encountered "no" votes, but it still passed (7-4). It then passed the Senate unanimously (28-0), and the Assembly again unanimously on reconciliation (77-0).[353] It was approved by the governor on July 2, 1979.[354]

The language of AB 204 drew heavily on the thoughts, ideas, and specific language developed at Cowell, PDSP, and CIL. The bill was enacted as Section 1, Chapter 8, added to Part 2 of Division 10 of the Welfare and Institutions Code. The first section (§19800) recognized the need for state assistance of disabled individuals in their attempts to live outside institutions. It then stated that funding would be allocated to "to maintain the services provided by existing independent living centers which provide services to disabled individuals." The legislature did "Vest in the Department of Rehabilitation the responsibility and authority for the encouragement of the planning, developing, and funding of independent living centers." The Department of Rehabilitation was to "consult with existing independent living centers in this state regarding

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[347] Letter from Ed Roberts to Chairman of the Assembly Human Resources Committee Richard Alatorre, March 6, 1979, in California State Archives, Department of Rehabilitation, R204.004:20, (Box 3).

[348] "Assembly Final History, Volume 1, California Legislature at Sacramento, 1979-80 Regular Session," 196; "Day in Sacramento," *The Los Angeles Times*, January 4, 1979, 37.

[349] "Assembly Final History," 196; "Sacramento Summary," *The Hanford Sentinel*, March 7, 1979, 7; "Sacramento Summary," *The Ventura County Star-Free Press*, March 7, 1979, 36.

[350] "Amendments to Assembly Bill No. 204 as Amended in Assembly April 5, 1979" May 2, 1979, in California State Archives, Assembly Ways and Means Committee, Bill Files - LP 190:11.

[351] "Assembly Final History," 196; "Thursday in Sacramento," *The Napa Valley Register*, April 27, 1979, 17; "Help For The Handicapped," *The Sacramento Bee*, May 2, 1979, 36.

[352] "Assembly Final History," 196; "Capital Calendar," *The Tulare Advance-Register*, May 24, 1979, 5.

[353] "Assembly Final History," 196; "Capital Calendar," *The Tulare Advance-Register*, June 23, 1979, 5; "Sacramento Summary," *Santa Cruz Sentinel*, June 24, 1979, 7; "Friday in Sacramento," *Ukiah Daily Journal*, June 24, 1979, 2; "Capitol Highlights," *The Sacramento Bee*, June 26, 1979, 8.

[354] "Assembly Final History," 196; "Monday in Sacramento," *The Napa Valley Register*, July 3, 1979, 3; "Bill Provides Aid For Disabled Living Centers," *The Sacramento Bee*, July 3, 1979; "Brown signs bill to aid the disabled," *Ventura County Star-Free Press*, July 3, 1979, 2.

funding procedures and decisions."[355] Already there was an emphasis on incorporating the independent living programs that were run by people with disabilities into the decision-making process within CADR. A major aim of the activists at Cowell Hospital and PDSP was the primacy of input from those with disabilities, and now CADR was explicitly required by the legislation to consult with the ILCs about funding procedures and decisions.

Hale Zukas stated three basic principles of PDSP and CIL. All three were embedded in the statute. The first principle was: "Those who know best the needs of disabled people and how to meet those needs are the disabled themselves." The role of those with disabilities and the primacy of their agency can be found in §§ 19801(a) and 19801(b), with the requirement that the majority of board members must be comprised of disabled individuals and the staff "shall include as large a proportion as is practicable of disabled individuals." The second principle was: "The needs of the disabled can be met most effectively by comprehensive programs which provide a variety of services." The comprehensive scope of programs and services can be found in §§ 19801(c) and 19801(d), featuring the list ILCs were to provide according to the statute, which was almost word-for-word the same as those listed by PDSP and CIL. The third principle was "Disabled people should be integrated as fully as possible into their community."[356] The integration of individuals with disabilities into the community was addressed in §§ 19800 and 19801(d), which explicitly stated the legislature's intent to "assist [disabled] individuals in their attempts to live fuller and freer lives outside institutions," and also provided services such as transportation, mobility assistance, and communication assistance. The activists' words and intent were inscribed in state law.

In 1972 Larry Biscamp, a Cowell Hospital resident who was one of the students Withington deprived of funding, and Herbert Willsmore, the first president of the Rolling Quads,[357] had written a report with another undergraduate, Judy Taylor, explicitly defining PDSP as a counterbalance to CADR. These three founding members of CIL had argued in their college paper that organizations like PDSP would promote the agency and independence of individuals with disabilities.[358] That position from their college paper was now state law.

There are countless stories from every disability activist – from Hessler confined to a hospital listening to French tapes, to Zukas's mother told by doctors that he should be institutionalized, to Roberts told by CADR that he would never work, to the conflicts at Cowell Hospital with Lucile Withington, to the early reports and studies by student activists on rehabilitation more broadly. Throughout there has been a constant struggle for the primacy of agency for those with disabilities. AB 204 codified that agency.

The language of the statute also followed the language of PDSP's founding language with respect to services provided. Section 19801(c) stated that an ILC "shall provide, but not be limited to, the following services to disabled individuals: (1) Peer counseling, (2) Advocacy, (3) Attendant Referral, (4) Housing assistance and (5) Other referrals." Section 19801(d) would also

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[355] Chapter 191 in *Statutes of California and Digests of Measures, Volume 1, 1979, 1979-80 Regular Session*, Compiled by Bion M. Gregory, Legislative Counsel, 420.

[356] Susan Pflueger, "Independent Living: Emerging Issues in Rehabilitation" for the Institute for Research Utilization, in Edward V. Roberts Papers, 1975-1998, The Bancroft Library, U.C. Berkeley, BANC MSS 99/34, Carton 1; Chapter 191, *Statutes of California*, 420-421.

[357] Grimes, oral history, 42-45; "Autobiographical Summary," Herbert Willsmore, no date, in Herbert Willsmore Papers, The Bancroft Library, BANC MSS 99/249c, 2; Lucile Withington, oral history, 85-87.

[358] Larry Biscamp, Judy Taylor, and Herbert Willsmore, with Charles Cole, "An Evaluation of Rehabilitation Counselor Training Programs from the Perspective of Disabled Clients," Working Paper, May 1972, Bancroft Library, pf HD7255.5 .B5 1972, 4.

provide "other services and referrals…such as transportation, job development, equipment maintenance and evaluation, training in independent living skills, mobility assistance, and communication assistance."[359] This language was derived straight from disability activists at Cowell Hospital and PDSP. Recall that when PDSP was founded, together with its non-university affiliated CIL, it was for attendant care, transportation, referrals, peer counseling, and wheelchair maintenance.[360]

The explicit language of AB 204 reflected the concepts of independent living developed by these student activists-turned-bureaucrats. Their work at the university, nonprofits, and government offices culminated in a statute that provided funding for the ILCs they had created, in a way that recognized the agency of those with disabilities and provided the services that they themselves said they needed.

IV. The Impact of AB 204

AB 204 funding was conditional on a report to the legislature and governor assessing different metrics of the ILCs funded by the statute. It required the evaluation to measure the following: "(a) the number and description of disabled individuals by disability, who receive services from the independent living centers; (b) the range of problems presented by the individuals served and the services provided in response to those problems; (c) the number of individuals who moved from an institutional setting to a more independent setting by type of setting; (d) the number of individuals who entered vocational rehabilitation or employment; (e) the impact of the services on medical and supportive service costs; (f) the impact of the services on the disabled individuals participation in family and community activities; (g) the cost and savings to the General Fund of providing the services; (h) Other sources of funding independent living centers; and (i) other information specified by the department."[361]

Two reports on AB 204 and independent living in California were generated in March of 1980 to describe the impact of the legislation. The first was a report produced by the independent Berkeley Planning Associates (BPA) and sent to CADR on March 1, 1980 (the BPA Report).[362] It was a thorough analysis based on a methodology of sending a survey to a random sampling of center clients, as well as site visits to each center and interviews with providers, administrators, and CADR staff.[363] During the month of March, 1980, this report was condensed by CADR and its parent Health and Welfare Agency, and then sent to the state legislature on

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[359] Chapter 191, *Statutes of California*, 420-421.

[360] Cathrine Caulfield, "First Woman Student in the Cowell Program, 1968," an oral history conducted in 1996 by Susan O'Hara in *University of California s Cowell Hospital Residence Program for Physically Disabled Students, 1962-1975: Catalyst for Berkeley s Independent Living Movement*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000, 139-140; Linda Perotti, "An Employee Perspective on the Early Days of the Cowell Residence Program, Physically Disabled Students' Program, and the Center for Independent Living," an oral history conducted by Kathy Cowan in 1998, Oral History Office, Bancroft Library, U.C. Berkeley, 2000, 126-132, 138; "Proposal for renewing Special Services' grant," fiscal year 1971, signed by John Hessler, in Hale Zukas Papers, The Bancroft Library, U.C. Berkeley, BANC MSS 99/150c, 5, 10-11.

[361] Chapter 191, *Statutes of California*, 421.

[362] "Evaluation Report on the State's Independent Living Centers Funded by AB 204 Final Report" Submitted to CADR by Susan Stoddard, Project Director, Berkeley Planning Associates, March 1, 1980, in California State Archives, Department of Rehabilitation, R204.013:4, hereafter, "Evaluation Report, BPA."

[363] Evaluation Report, BPA, ix.

March 30, 1980 (the CADR Report).[364] The CADR Report primarily focused on the highlights of the BPA Report (hereafter, I will use "the Reports" when referring to both).

The BPA Report attempted to quantify the efficacy of the ILCs, and in most categories required by the statute it was successful. For the composition of clientele, the BPA Report found that across all ILCs the prevalence of orthopedically disabled clients outnumbered any other group. Most clients were disabled as adults (after age 22) and were "long-term disabled," meaning they had been disabled for eleven or more years. The BPA Report also noted that the clientele tended to be "well-educated" (some college, finished college, and post-graduate work categories made up the majority, outnumbering finished high school or less education).[365]

The three needs most frequently reported were advice from a counselor, information about other sources of aid, and assistance in finding an attendant. While there was no exact predominant need, the BPA report noted that many clients called or visited to receive general advice and develop contacts and social networks, rather than reaching out to address an exact specific issue.[366] The three major services offered in all centers studied were peer counseling, attendant referral, and general advocacy.[367] According to respondents, the centers also helped find housing and transportation services.[368]

The BPA Report stressed that the move to independent setting provided psychological and symbolic value, as well as enabling clients to move beyond dependent behaviors. Movement to an independent setting was meant to allow the individual to be free to make decisions about day-to-day activities such as when to get up, eat, sleep, go outside, and so forth.[369] Between first contact with a center and the time of the survey (approximately two years), twenty-eight percent of the respondents changed their housing situation, and the majority of those had moved out of an institution.[370] The BPA Report also quoted feedback from clients about their new-won independence, with some clients saying: "My morale and outlook on life is much more positive. Thank you." and "The center is making me independent." Ultimately sixty-five percent of clients surveyed reported that the centers "had a positive impact on their housing situation."[371]

Finding employment was a primary service at only four of the centers receiving AB 204 funding. Staff at the centers stated this was in large part due to the services already offered by CADR. Yet it was still an important component of independent living, as one client stated, "Getting a job is very important—especially when you have a disability. It is so necessary in this day and age for a positive self-image—as well as for the obvious – money." While the centers might not have focused as much on job training, they did demonstrate that persons with disabilities could be employed, by their own employment of persons with disabilities as staff members. One client wrote, "Aside from practical help the example of disabled people who are working. They are wonderful role models." The ILCs that were surveyed reported working

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[364] "Special Report to the Legislature: Independent Living Centers Evaluation and Recommendations (Authorized by Assembly Bill 204, Chapter 191, Statutes of 1979)," State of California, Health and Welfare Agency Mario G. Oblego, Secretary, and Department of Rehabilitation, Edward V. Roberts, Director, March 30, 1980, in California State Archives, Department of Rehabilitation, R204.004:21, hereafter, "Special Report, CADR."

[365] Evaluation Report, BPA, 5, 8.

[366] Evaluation Report, BPA, 13, Special Report, CADR, 8.

[367] Evaluation Report, BPA, 16.

[368] Evaluation Report, BPA, 22, 24.

[369] Evaluation Report, BPA, 25.

[370] Evaluation Report, BPA, 27.

[371] Evaluation Report, BPA, 31-32.

closely with CADR through referrals and visits from CADR counselors.[372] However, there was only a slight change in increased participation in the work force as a result of contact with the centers.[373] When the BPA Report distinguished between centers with services explicitly devoted to helping clients find employment, rather than all clients including those at centers without these services, however, the impact was dramatically positive. For clients receiving those services, seventy percent reported positive effects in finding a job or receiving help with an employer. One client wrote, "I have become more independent. I am holding down my first full-time job and I can relate more easily to other people with disabilities."[374]

For health costs, the BPA reported a forty-seven percent decrease in the number of clients surveyed who needed hospitalization services. However, staff pointed out that more mobility among clients would likely lead to greater use of services such as dentistry and annual physician appointments. Assessing exactly whether the costs would go up or down due to the conflation of these trends (less hospitalization but more utility of services) made the exact impact difficult to measure.[375] There was an increase in the number of people using attendants and in the number of hours attendant services were used. The report also noted that SSI and SSDI payments increased. The BPA Report was reluctant to draw exact cause-and-effect conclusions based on these numbers, but there was a possibility that the centers made individuals more aware of such services and therefore increased the use, and cost, of them.[376]

It was more difficult for the BPA to assess the effect on family and community relationships. Most clients reported no impact on family and community participation. When there was an effect, however, it was positive. According to the BPA Report, "about one-third of the clients responding indicated a positive effect on social relationships with friends and in the community." Direct feedback from clients helped to illustrate the nature of that positive impact. One client commented, "This center gave me an opportunity to meet other disabled persons, successfully living independently, and helped me put my own situation and disabilities into proper perspective. In other words, it gave me a realization of all the things I <u>am</u>, not what I <u>am not</u>. I feel more confident about myself and am much more vocal in what I believe in." Another client said, "This center has helped me to get my self-respect. They have helped me to be useful. Helped me to be needed. They have helped me build up my self-image so much that I feel free to ask a woman out for a date. I have only started dating within the last four years."[377] Despite the difficulty in assessing family and community engagement, such feedback suggested a strong positive impact from contact with the centers.

For funding, some centers were exploring other options, but at the time of the report many were relying on continued funding from the state. Some looked for funding through fee-for-service reimbursement, other grants, and private funding, but state funding continued to be the foundation upon which most centers relied to continue operating.[378] For ultimate costs or benefits to the state and public, the BPA Report tried to assess competing sides of the ledger. The centers put clients in contact with services such as employment training and attendant care, which increased costs. As the centers grew and continued to rely on state funding, they would need more state funding. However, the BPA Report also noted that clients were hospitalized less,

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[372] Evaluation Report, BPA, 33-34 (quotes here); Special Report, CADR, 12.
[373] Evaluation Report, BPA, 36.
[374] Evaluation Report, BPA, 39-40.
[375] Evaluation Report, BPA, 42-44; Special Report, CADR, ii.
[376] Evaluation Report, BPA, 54.
[377] Evaluation Report, BPA, 62-63, emphasis in original.
[378] Evaluation Report, BPA, 69-74.

saving Medi-Cal funds, and that job earnings for clients increased. Finally, there was recognition that centers resulted in benefits difficult to measure in dollars, such as positive outlook, hope, and meaning and self-respect for clients. Two examples are illustrative: "It has made me understand that being disabled is not the end of the world and that I can do just about anything I want to," and "What I would say is most important is the center helped me realize that life does not end in a wheelchair."[379]

The Reports were submitted less than a year after the governor signed the law. Although some of the metrics were difficult to analyze, and there were some rising costs in public funds, the feedback from clients and the increase in services suggest the centers were making a positive impact on the disabled population in California. This positive impact was made possible due to advocrats such as Tom Bates, Ed Roberts, John Hessler, Jim Donald, and many others.

On the CADR website today one can find a banner that reads "Employment and Independent Living for Californians with Disabilities since 1963."[380] While the department has existed since 1963, independent living only became a part of its mission through the efforts of disability activists operating inside and outside of government in the two decades after students started living in Cowell Hospital while attending U.C. Berkeley.[381] Still, that mission continues to be a part of the department today. The department's webpage states that:

> "The California Department of Rehabilitation (DOR) works in partnership with consumers and other stakeholders to provide services and advocacy resulting in employment, independent living, and equality for individuals with disabilities. DOR administers the largest vocational rehabilitation and independent living programs in the country... Independent living services may include peer support, skill development, systems advocacy, referrals, assistive technology services, transition services, housing assistance, and personal assistance services."[382]

Resulting from AB 204 and the tenure of disability activists at CADR, the department continues to provide independent living services explicitly listed in PDSP's founding documents by Cowell Residents, such as peer support, housing assistance, and personal assistance services.

In the months following the passage of AB 204, Ed Roberts reflected on the previous ten years and the shift in social and legal understandings of disability. He wrote,

> "During the 1970's persons with disabilities from all parts of the country began to share their dreams and began to build models which would prove to our society that these dreams could become a reality…In the early seventies, we began to take our lives in our own hands…In looking back at the 1970's, I view it as a decade in which together we disproved myth after myth about persons with disabilities…When the decade began virtually all of my friends with disabilities were dependent on public assistance. They now hold jobs as computer programmers, lawyers, workers in the helping professions, teachers, and yes, even as heads of bureaucracies. (My lot and happily so.)"[383]

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[379] Evaluation Report, BPA, 76-78.

[380] https://www.dor.ca.gov/

[381] See Various Reports, No attributed author/s, in California State Archives – Department of Rehabilitation – F3934:1 and F3934:4, in Administrative Files – Projects, Box 1.

[382] https://www.dor.ca.gov/Home/DepartmentOverview.

[383] Edward V. Roberts "A Personal Perspective on the 80's," in *Amicus*, published by Center for Law and the Handicapped at the University of Notre Dame, Vol 4, No. 5 & 6 September/December 1979, 247, in Edward V. Roberts Papers, 1975-1998, The Bancroft Library, U.C. Berkeley, BANC MSS 99/34, Carton 1.

The decade had started with the rebellion against Withington at Cowell, and the founding of PDSP and CIL. It would end with the passage of AB 204 establishing independent living in California state law. It was not only the activists, but the counselors, legislators, hospital directors, and university administrators who worked with the activists that achieved these goals. Ed Roberts was not the only advocrat. Although he may have been one of the more zealous and fervent of them, they existed on a spectrum. Henry Bruyn, Tom Bates, John Hessler, Jim Donald, Arleigh Williams, Edna Brean, Jean Worth, and Phil Morse were all advocrats, too, and all worked to create opportunities for those with disabilities.

PDSP and CIL both still exist. PDSP is now the Disabled Students' Program (DSP)—dropping the "physically." U.C. Berkeley instructors are sent emails from DSP in the weeks before every semester, with letters that state the needs and accommodations of every student with a disability. DSP continues to work with students to provide the best possible experience at the university. CIL in Berkeley also continues its operations. Anyone in need of its services can take BART to Ashby Station. They would then leave through the exit from the BART Station featuring a plaque recognizing Hale J. Zukas's outstanding leadership and service in making transportation more accessible to people with disabilities. After exiting, they can use the ramp and elevator to enter the Ed Roberts Campus, where people working at CIL are waiting to offer a list of services, first formulated by Cowell residents over fifty years ago.

Conclusion

I do not know if independent living centers could have helped Lynn Thompson, because I do not know what was going on in her life. There may have been more to her sadness and despair than the frustrations of disability law, with its restrictive benefits and deterrents to opportunity. But in her suicide note, she explicitly blamed the limitations of welfare benefits and their impact on a disabled person's capacity to work for her plight. Law was at the heart of this devastating impact. Amendments to federal statutes had created the benefits. The absence of California state laws and the limited promulgation of the few that were on the books limited her options. A statute that could have provided more funding for services to people struggling like Thompson was two years away. It is difficult to imagine that there would not have been some benefit for Thompson from the independent living movement and AB 204.

This dissertation has illustrated the centrality of law in defining disability in California during the twentieth century. It has shown how law was woven into the medical evaluations of people's capacities to work in the eighteenth and nineteenth century. From immigration entry ports to worker compensation laws to federal acts covering veterans' benefits and rehabilitation to eugenics inscribed in judicial decisions, the law was deeply embedded in assessments and evaluations of disability throughout American history.

Law continued to be a crucial component in determining access to health care for those with disabilities who could not work and were not covered by health insurance through employment. Medical professionals through the California Medical Association protected the profession through legislation that determined who could practice medicine, and then used litigation to push paying customers out of public hospitals and into private physicians' offices, leaving underfunded public care for the indigent disabled. The emergence of group prepayment plans sponsored by employers expanded health care, but it had two major impacts on those considered unemployable. First, and most obviously, it excluded them. Someone impaired and struggling to find work could not take advantage of this new health care system. Second, it undermined the possibility of public options through its insistence that it was not socialized medicine. It touted its expanded coverage as decreasing the need for public health care systems. The two-tiered health care system of fee-for-service and prepaid plans might have helped the employed, but it excluded the unemployed and those medically considered unable to work form coverage. Health care predicated on employment left those on the fringes without access to high quality health care.

Despite the medicalization of disability, and despite the shifting basis for provision of health care in the 1930s and 1940s that left out the disabled, there was a shift in the 1960s and 1970s in how disability was conceptualized, and how care would be provided. Independent living concepts developed through the lived experience of student activists at U.C. Berkeley in the 1960s. Surrounded by the Free Speech Movement and the Civil Rights Movement, students living at Cowell Hospital reframed their "medically disabled" condition as something else. They looked to the institutions and the officials there the problem. It was not their own lack of mobility that was the issue, it was the discrimination from counselors and employers, as well as the physical environment that prevented them from achieving their social and professional goals. Working both with and against nurses, counselors, and administrators at U.C. Berkeley taught these students how they could implement change not only in their living conditions, but in the regulations and policies of the institution. They formulated concepts for a new framework of disability, one that focused on the agency of the individual with the disability, rather than the medical assessment of the doctor or CADR counselor. This was a profound shift away from the medical evaluations used to assess a capacity for work and toward a fuller understanding of an individual's ability to exist in their community.

The new conception of disability provided new opportunities for those with disabilities at the university and in nonprofits, but it was still an emerging organized effort that limped from grant to grant for its operational functionality. The new independent living centers pioneered by disability activists needed a firmer foundation upon which to offer their services and to expand to serve others. Despite the often-confrontational nature of disability activists and state officials, it was also apparent that these two groups could actually work together well and could continue to do so in pursuit of sustainable funding for centers throughout the state. Ed Roberts was appointed director of CADR, and then was joined by John Hessler and Jim Donald to work as advocating bureaucrats inside government—advocrats. Joining forces with Assemblyman Tom Bates, as well as other nonprofits like ILCs and health care charities, these advocrats changed California state law to address disability as a social *and* medical condition, and to provide essential services to assist Californians with disabilities in engaging in social and economic activities in their own communities.

This dissertation has tried to challenge a binary narrative of noble activist versus oppressive state forces. There were clearly problems with the split in health care between private and public systems focused on different clienteles—the private system that treated the young, healthy, and employed, while the public system treated the elderly, chronically ill, and unemployed. However, prepayment plans did expand health care coverage for workers who otherwise had struggled to find care. Doctors Sydney Garfield and Cecil Cutting in particular passed on other potentially more lucrative career paths to be a part of an innovative expansion of health care coverage. It could have been expanded further than they contemplated, and future generations of physicians and health care professions should endeavor to keep expanding it, but it is worth noting the positive effect of their efforts. Once considered employable, and once employed, Californians with disabilities would obtain health care through employment-based prepayment plans.

There were clearly problems with the California Department of Rehabilitation, and there likely still are. The evaluations of individuals with disabilities that its counselors produced could be limiting. However, CADR was operationalized to help students enter U.C. Berkeley through Cowell Hospital, and many students of that era credit CADR's accommodations and funding in allowing them to receive a college education. They have stressed that education was a key to overcoming the barriers raised by physical impairment. In order to open social and economic opportunities, they recognized they needed to use their intellect. CADR's adaptability to these new demands helped provide those opportunities.

Eventually the California state legislature proved amenable to altering the conception of disability in state law. It was clearly a challenge for proponents of AB 204 to pass the statute, as can be seen by the failure of a prior version just the year before. But once it was introduced, galvanized supporters were able to push for its passage without prohibitive friction. At most stages it passed committees and through both the assembly and senate with unanimous votes in favor. Activists need receptive state institutions, officials, and laws to implement change, and they found that in the California state legislature.

Changing a legal concept is a multifaceted process. This dissertation has shown that law can define a condition like disability in limiting ways, as it did during the eighteenth and nineteenth centuries. Law can have detrimental impact on real people, as it did on the disabled unemployed in California during the 1930s and 1940s. However, the law can also be changed to reflect new conceptions and new definitions. Young students originally dismissed as incapable of flourishing were able to engage in activism, advocacy, and bureaucratic maneuvering to change state law and provide funding, resources, and opportunities for future generations.

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