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Berkeley Women in the Disability Rights Movement

Compiled by Mary Tan, Class of 2020 & 150W Project Assistant



UC Berkeley students and staff from the Disabled Students' Program with staff from the Center for Independent Living (CIL) October 1987. Photo: Disabled Students Program Photograph Collection at the Bancroft Library, UC Berkeley.

2020 marks the 150th anniversary of the admission of women to the University of California, as well as the 30th anniversary of the passage of the Americans with Disabilities Act (ADA) in 1990. At the intersection of these identities lived brilliant advocates of disability rights. The legacy of some of these local catalysts were presciently preserved by Susan O'Hara through the Bancroft Library's Disability Rights and Independent Living Movement (DRILM) Oral History Project.

As a cradle of social change in the 1960s, the city of Berkeley gave rise to the Disability Rights and Independent Living Movement. The Civil Rights Movement inspired a cultural shift in the idea that people with disabilities have the right to self-determination. UC Berkeley's female staff, alumnae, and allies helped change the social perceptions of people with disabilities. Leaders like Zona Roberts promoted equitable access to life opportunities as her son, activist Edward Roberts, became the first student with severe physical disabilities to attend Cal. Judith Heumann mobilized communities to oppose discrimination on the basis of disability. We feature some of the many women who contributed to this moment in time and advanced the field of disability studies.



Susan O'Hara - DSP Director and Independent Living Advocate

Lifelong educator and polio survivor Susan O'Hara empowered fellow wheelchair users and people with disabilities to lead independent and fulfilling lives. The Illinois native enrolled in classes at UC Berkeley during the summer of 1971 to participate in the Cowell Residence Program, one of the earliest experiments with residential accommodations for students with significant physical disabilities. O'Hara was amazed by the established system of care and availability of resources at the university.

In 1975, the Cowell Residence Program evolved into the Disabled Students Residence Program (DSRP) and O'Hara was hired as the new program coordinator. She reassured concerned families and explained the importance of autonomy for people with disabilities to achieve life goals and actively participate in social life, a core tenet of the Independent Living Movement. After retirement in 1992, O'Hara reconnected with oral historian Willa Baum to establish the DRILM oral history collection at the Bancroft Library. Together, they facilitated over 100 interviews and produced the *Disability Rights and Independent Living Oral Histories* archive. True to the mantra of the disability rights movement: "nothing about us without us," O'Hara staffed the project with interviewers from the disability community.

Excerpt from "Susan O'Hara: (1938-2018): A Champion of Disability Rights and Independent Living" by Mary Tan
Photo: San Francisco Chronicle obituary, 2018



Cathy Caulfield, 1966.

Cathrine Caulfield - First Woman in the Cowell Residence Program

Cathrine Caulfield was the first female student in the Cowell Residence Program (1968), participated actively, and was well-acquainted with other residents. In subsequent years in the community, she was involved in the early days of the Physically Disabled Students' Program [PDSP] and the Center for Independent Living. Cathy's oral history conveys enthusiasm for her experiences in Berkeley—the daily conversations with other students at Cowell, the growing sense of community and empowerment, the embryonic thoughts that led to the founding of PDSP as well as the Disabled Community Health Clinic. She mentions other students who were in the Cowell program when she was there, and pays particular attention to John Hessler and Ed Roberts. She also describes the excitement of moving to her first apartment after Cowell.

Excerpt and photo from *Disability Rights and Independent Living Movement Oral History Series* - University of California's Cowell Hospital Residence Program for Physically Disabled Students, 1962-1975: Catalyst for Berkeley's Independent Living Movement



Judith Heumann, MPH '75 - Disability Activist

Judy Heumann received her master's in Public Health at UC Berkeley and was critical in organizing the 504 sit-in of 1977. For 25 days, Judy and well over 100 disabled people occupied the San Francisco office of the United States Department of Health, Education, and Welfare and demanded enforcement of Section 504 of the Rehabilitation Act of 1973, which stated that no institution receiving federal funding could exclude people on the basis of their disability.

Judy's activism in 1972 was critical to getting Section 504 written in the first place, and she and other disabled people were tired of it being completely unenforced—schools, cities, and buildings were still inaccessible despite the law's promise. Schools lacked elevators to allow disabled students to get to their classrooms; sidewalks lacked defined dips in the corners and thus often forced wheelchair users to take inconvenient, circuitous routes to their destinations or left them stranded. In response, disabled people occupied government buildings across the country in protest. The San Francisco demonstration was the longest lasting and arguably the most successful, largely thanks to the motivating force that was Judy Heumann.

Excerpt from "Crip Camp and Judy Heumann: Studies in Movement Snapshots" by Annabelle Long
Photo: New York Daily News Archive / Getty Images



Debby Kaplan, 1999.

Deborah Kaplan, JD '76 - Attorney & Spokesperson

Deborah (Debby) Kaplan left Berkeley after graduation to work for Ralph Nader in Washington where she established the Disability Rights Center and connected with other leaders in the movement. She was a member of the board of the American Coalition of Citizens with Disabilities and actively involved with passage of Section 504 of the Rehabilitation Act of 1973. She testified at hearings during the 504 sit-in at the Federal building in San Francisco. While in the Washington area, she worked at the Public Interest Law Center of Philadelphia, did a study for the Women's Legal Defense Fund, and began a lifelong interest in prenatal testing, genetics, and right-to-life issues.

She returned to the Bay Area in 1980 to work at the Disability Rights Education and Defense Fund on behalf of people with developmental disabilities and employment discrimination. In 1986 she moved to the World Institute on Disability [WID] where she laid the groundwork for inclusion of the needs of people with disabilities in emerging communication technologies. Much of her work and that of the Technology Policy Division of WID, which she developed, is evident in the Telecommunications Act of 1996. After leaving WID for several years, she returned in 1997 and was appointed its executive director in 1998.

Excerpt and photo from *Disability Rights and Independent Living Movement Oral History Series - Attorney, National Policy Advocate, and Spokesperson for Disability Rights Organizations, 1976-1990s*



Susan E. Sygall, BS '76 - Cofounder of MIUSA

Susan Sygall's early interest in sports and athletics led her to the University of Colorado with a major in recreation. She became disabled in an automobile accident soon after she enrolled. In her interview, she says she was inspired by her vocational rehabilitation counselor and her parents, who had survived the Holocaust and had always encouraged her to live each day of her life to the fullest. She soon discovered the opportunity to complete her education as part of the Disabled Students' Program at UC Berkeley in 1973.

At Berkeley, Ms. Sygall cofounded the Disabled Women's Coalition and the Berkeley Outreach Recreation Program, for which she served as executive director until 1978. She has traveled extensively, before and after a year in Australia as part of a Rotary scholarship to the University of Queensland. Ms. Sygall is currently executive director of Mobility International USA, an international travel and exchange program for people with disabilities which she cofounded in 1981.

Excerpt from *Disability Rights and Independent Living Movement Oral History Series* - Cofounder and Director of Berkeley Outreach Recreation Program and Mobility International USA, Advocate for Women's Issues

Photo: Bureau of Educational and Cultural Affairs / Youtube - Susan Sygall's Introduction to Lives Without Limits



Zona Roberts - DSP Counselor & Parent Advocate

Zona Roberts existed in Berkeley as a mother before she existed here as a student. She lived with her sons Ed, Ron, Mark, and Randy in a pale green house she rented on Ward Street, a few blocks west of the hustle and bustle of Telegraph Avenue and a few blocks east of Shattuck. When Zona moved in, she had a ramp installed in the back to allow Ed to get inside. Ed Roberts, Zona's eldest son and a political science major at UC Berkeley, was the first wheelchair user ever admitted to the school, and virtually nothing in the city was wheelchair accessible when he arrived on campus in 1962, including his mother's home. The green house, as it came to be known, acted as a sort of safe haven for the Roberts family and their friends. It was a family home for the community, not just Zona and her sons.

UC Berkeley promised a new world of opportunity for both her and Ed, when previously, his disability had meant neither of them was optimistic about what the future would hold, and her role as mother and caretaker left little room for imagining a life outside their home. But Berkeley was different; here, Ed was a student and leader, and eventually, so was she. In her oral history, when the conversation veered away from her time in Berkeley, she'd direct it back with references to the green house. The landscape of her college experience seemed to define it. She became acquainted with Berkeley alongside and behind Ed.

Excerpt from "From the OHC Archives: Zona Roberts and Learning to Walk Backwards" by Annabelle Long
Photo: *Disability Rights and Independent Living Movement Oral History Series* - Counselor for UC Berkeley's Physically Disabled Students Program & the Center for Independent Living, Mother of Ed Roberts



Linda Perotti - DSP Administrative Staff & Support

Linda Perotti arrived in Berkeley a year after the Free Speech Movement got its raucous start on the steps of Sproul Hall, the university's now-famous administrative building on the southern edge of campus, and she was more concerned with keeping up with her coursework than with any of the growing number of antiwar and civil rights movements that would come to characterize Berkeley in the late 60s. This disinterest was not from lack of care, but rather what Linda described as a naturally apolitical disposition.

The next few years of Linda's life track nicely alongside the development of the Disabled Students' Program (DSP) and the Center for Independent Living (CIL)—she stopped taking classes during what would have been her senior year, and spent a lot of time with the organizers behind DSP and CIL as the programs swelled in size and scope. Still, though, movement politics were uninteresting to her. She cared about streamlining attendant referral services—everything was still word of mouth—and developing peer counseling services for disabled students, and helping the organizers accomplish other goals that they had, but she understood her role to be primarily administrative.

Excerpt from "From the OHC Archives: Linda Perotti, Apolitical Advocate" by Annabelle Long

Photo: *Disability Rights and Independent Living Movement Oral History Series* - An Employee Perspective on the Early Days of the Cowell Residence Program, Physically Disabled Students' Program, and the Center for Independent Living



Professor Susan Schweik- Associate Dean of Arts and Humanities

Susan Schweik's last book was *The Ugly Laws: Disability in Public*. She is completing a book tentatively titled *Unfixed: How the Women of Glenwood Asylum Overturned Ideas about IQ, & Why You Don't Know About Their Work*. In 2018 she was awarded the Jeanette K. Watson Distinguished Visiting Professorship at the Humanities Center, Syracuse University. A recipient of Berkeley's Chancellor's Award for Advancing Institutional Excellence and UC's Presidential Chair in Undergraduate Education, she has been involved with the development of disability studies at Berkeley for over 17 years. She was co-coordinator of the Ed Roberts Fellowships in Disability Studies post-doctoral program at Berkeley (coordinated by the Institute for Urban and Regional Development). She has taught and co-taught undergraduate courses in Disability and Literature, Discourses of Disability, The Disability Rights Movement, Disability and Digital Storytelling, Psychiatric Disability, Literature and Medicine, and Race, Ethnicity and Disability, among others, and graduate courses in Body Theory and Disability Studies and Advanced Disability Studies. Her other teaching and research interests include twentieth century poetry, late nineteenth century American literature, women's studies and gender theory, urban studies, war literature and children's literature. She is a recipient of Berkeley's Distinguished Teaching Award.

Excerpt from UC Berkeley English Department faculty profile
Photo: UC Berkeley Townsend Center for the Humanities



Professor Georgina Kleege - Scholar in Disability Studies and Creative Writing

Georgina Kleege joined the English department at the University of California, Berkeley in 2003 where in addition to teaching creative writing classes she teaches courses on representations of disability in literature, and disability memoir. Her collection of personal essays, *Sight Unseen* (1999) is a classic in the field of disability studies. Essays include an autobiographical account of Kleege's own blindness, and cultural critique of depictions of blindness in literature, film, and language. Many of these essays are required reading for students in disability studies, as well as visual culture, education, public health, psychology, philosophy and ophthalmology. *Blind Rage: Letters to Helen Keller* (2006) transcends the boundaries between fiction and nonfiction to re-imagine the life and legacy of this celebrated disability icon. Kleege's latest book, *More Than Meets the Eye: What Blindness Brings to Art* (2018) is concerned with blindness and visual art: how blindness is represented in art, how blindness affects the lives of visual artists, how museums can make visual art accessible to people who are blind and visually impaired. She has lectured and served as consultant to art institutions around the world including the Metropolitan Museum of Art in New York and the Tate Modern in London.

Excerpt from UC Berkeley English Department faculty profile
Photo: UC Berkeley Othering & Belonging Institute



Professor Karen Nakamura - Chair of Disability Studies Research Cluster

Karen Nakamura is the Robert and Colleen Haas Distinguished Chair in Disability Studies and a Professor of Anthropology and graduate advisor for the UCB-UCSF Joint Program in Medical Anthropology, UC Berkeley. She is a cultural and visual anthropologist whose research focuses on disability, sexuality, and minority social movements in contemporary Japan. In 2006, she published *Deaf in Japan: Signing and the Politics of Identity*, an ethnography of sign language and deaf social movements. Her second project on psychiatric disabilities and community based recovery resulted in two ethnographic films and a book titled, *A Disability of the Soul: An Ethnography of Schizophrenia and Mental Illness in Contemporary Japan* (2014). Her books, films, and articles have resulted in numerous prizes including the John Whitney Hall Book Prize, the SVA Short Film Award, and David Plath Media Award. She is currently finishing a project on trans movements as disability in Japan while launching a new project on robotics, augmentation, and prosthetic technology.

Excerpt from UC Berkeley Othering & Belonging Institute and Anthropology Department faculty profile
Photo: WNPR / Chion Wolf



Assistant Professor Sunaura Taylor - Scholar & Artist in Environmental Humanities

Sunaura Taylor is an Assistant Professor in the Division of Society and Environment. Taylor is a scholar and artist who works at the intersection of disability studies, environmental humanities, animal studies, environmental justice, feminist science studies, and art practice. Her research situates disability and ableism as central forces shaping human relationships to the more-than-human world. Concerned with relationships between altered bodily capacity, vulnerability, and systems of exploitation across species and ecological boundaries, her works crosses a range of disciplines, mediums, and audiences. Taylor is author of *Beasts of Burden: Animal and Disability Liberation* (The New Press, 2017), which received the 2018 American Book Award. Along with academic journals, Taylor has written for a range of popular media outlets. Her artworks have been exhibited at venues such as the CUE Art Foundation and the Smithsonian Institution and is part of the Berkeley Art Museum collection. Among other awards, she has received a Joan Mitchell Foundation MFA Grant, two Wynn Newhouse Awards, and an Animals and Culture Grant.

Excerpt from UC Berkeley Department of Environmental Science, Policy, and Management faculty profile
Photo: sunaurataylor.com



Marsha Saxton, Lecturer - Director of Research at WID

Marsha Saxton is Director of Research and Training at World Institute on Disability (WID) as well as a lecturer in Disability Studies at the University of California, Berkeley. Marsha loves teaching and training, and has presented workshops and classes in recent years in Australia, Japan, Britain, Finland, Qatar, Canada, and the U.S. She was the recipient of the Irving Kenneth Zola Memorial Lecture award and has been interviewed on 60 Minutes about Wrongful Birth lawsuits and was a guest on Talk of the Nation with Ray Suarez, addressing issues of reproductive technologies, and the disability community's view of selective abortion. She has published three books, two films, and over one hundred articles and book chapters about disability rights, Personal Assistance, women's health, violence prevention and genetic screening issues. She has been a board member of the Our Bodies, Ourselves Collective, and served on the Council for Responsible Genetics, and the National Institutes of Health (NIH) Ethical, Legal, and Social Implications (ELSI) Working Group of the Human Genome Initiative. She is currently developing a collaborative health promotion program with Ed Roberts Campus partner organizations.

Excerpt and photo from the Othering & Belonging Institute at UC Berkeley



Arlene Mayerson, JD'77 Lecturer - Directing Attorney of DREDF

Arlene B. Mayerson has been the Directing Attorney of Disability Rights Education and Defense Fund (DREDF) since 1981. One of the nation's leading experts in disability rights law, she has been a key advisor to both Congress and the disability community for over three decades on major disability rights legislation, including the Handicapped Children's Protection Act as well as other legislation ensuring the special education rights of students with disabilities, and the Americans with Disabilities Act (ADA). At the request of members of Congress, Ms. Mayerson supplied expert testimony before several committees of Congress when they were debating the ADA, and she filed comments on the ADA regulations for more than 500 disability rights organizations. Ms. Mayerson has devoted her career exclusively to disability rights practice, representing clients in a wide array of issues. She has provided representation, consultation to counsel, and coordination of amicus briefs on key disability rights cases before the U.S. Supreme Court. She was appointed by the Secretary of the U.S. Department of Education to the Civil Rights Reviewing Authority, responsible for reviewing civil rights decisions of the Department. In 2012, Ms. Mayerson led the legal team that secured a historic settlement regarding application of the ADA to online commerce in *National Association of the Deaf, et al. v. Netflix*, which ensures 100% closed captions in Netflix's On-Demand Streaming Content within two years. Although this settlement can be appreciated purely for its value in increasing access to online entertainment, it has implications for the ever-growing provision of education, public benefits, healthcare, and other materials and services through streaming video and other technology. The ability to recognize and respond to such far-reaching issues emerging in disability rights law has been a hallmark of Ms. Mayerson's work throughout her career.

Excerpt from Berkeley Law Faculty Profile
Photo: Equal Justice Society