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## Interviews

# An Interview with Scot Danforth, Author of An Independent Man: Ed Roberts and the Fight for Disability Rights

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## Abstract

This interview features Scot Danforth, author of *An Independent Man: Ed Roberts and the Fight for Disability Rights* (University of California Press, 2025). Conducted on March 19, 2026, via Zoom, the interview explores Danforth's motivations for writing the biography, his eight-year research and writing process, and what he learned about Ed Roberts and the broader disability rights movement. Topics include the origins of the disability rights movement in Berkeley, the creative and political legacy of Roberts, and the ongoing urgency of disability rights advocacy.

*Keywords*: disability rights, Ed Roberts, biography, independent living movement, Berkeley, disability history

# An Interview with Scot Danforth, Author of

# An Independent Man: Ed Roberts and the Fight for Disability Rights

The following interview with Scot Danforth, author of *An Independent Man: Ed Roberts and the Fight for Disability Rights* (University of California Press, 2025), was conducted March 19, 2026, remotely via Zoom, by Raphael Raphael. Text may have minor revisions for clarity.

**RR:** I really enjoyed this book and think it's going to do amazing work in amplifying and magnifying the impact of this remarkable man. First thing, how did the idea for Independent Man first emerge? What made Ed Roberts the figure you felt you had to write about?

**SD:** It began with my own curiosity about how the disability rights movement in the United States began. Which, of course, no historian will tell you began in one place at one time. But I began by studying Ed Roberts and the Rolling Quads, which was a student group of activists in 1969 in Berkeley. And so that led to one academic article. But then I started thinking, well, these well-known disability rights leaders—you know, Judy Heumann, Ed Roberts, Hale Zukas—do people know about them? I mean, everyday people. Do they even have access to these stories? And there's so little written. I did academic, quote-unquote, research. But my goal all along, and thankfully my publisher got it, was to write for the public, to be able to tell stories that the public could take in. Because how this movement grew, and the people involved, and the incredible brilliance of it all, and the courage, and the fight—it's the kind of thing that everyday people on the street should know about. And I was kind of shocked that we didn’t have biographies of our leading disability rights leaders. We just don’t have those kinds of books. And Ed was right at the tip of my fingertips, because there I was, working on a Berkeley story, and I started realizing how fascinating it was, so I just ran with it.

**RR:** That really comes through in the accessibility of the work. It’s a page-turner.

**SD:** Good, I’m glad, because I realized at one point that in academic writing, people read it because they have to, they’re paid to. But out in the world, somebody said to me, why should I read till the next page?

**RR:** Exactly.

**SD:** And I thought, why should you read? Because there’s a really good story here, if I can figure out how to tell it.

**RR:** It’s clear in each page that you are doing that—why should I read to the next page? And it’s definitely very accessible for the public. And it almost seems like it would be sacrilege if it was dry, given his personality and life. How long did it take from initial idea to publication?

**SD:** 8 years of research and writing. Which meant I rewrote it many, many times.

**RR:** And what did your time actually feel like day-to-day? In the creation of the work.

**SD:** I ended up with a mantra, which was—because I was doing library research, archives, I was interviewing people—my mantra was, I can’t write this book. But I can do the work today.

And I just did it day to day to day, assuming that it would all add up. Because it's just too big. A life… The burden, to me, the burden of having to represent the life of Ed Roberts—that's too much for me to think I can do. At the beginning, I will tell you, I went immediately to start, and I met with his brother Mark, his younger brother, and I met with his mother, Zona. So I had sort of these two people expecting something. And I thought, oh boy, I better get going.

**RR:** Yeah. And Zona was up to a hundred and…?

**SD:** 105 she lived to, yes.

**RR:** Oh my goodness, that's amazing. Well, with this journey, how did the process of writing the book change the way that you understand Ed Roberts, and perhaps disability itself and the movement?

**SD:** Boy, I think… I hope it comes through that I learned about the creativity of Ed—and I try to write about many, many more people than Ed Roberts—but the creativity of conjuring up a valuable existence when the people around you are not granting you that, not assuming that. And so the incredible strength and creativity it takes to do that, especially—I know things are difficult now, but they were even worse in the 1950s and 1960s. And so you end up with a character like Ed, who was not just imaginative, but was over the top. He figured out that going far enough is never going far enough. You have to go too far. And he did everything bigger than big. The other thing was the whole theme of fighting, which I think runs through the book, that Ed learned very early on that if he was going to live a worthwhile life, a rich life, a life in the community, he was going to have to fight. And initially, it was just for himself. But wonderfully, at Berkeley, he joined together with others and found what we know as a movement. Which is—sometimes you have to fight for yourself, but if you fight with your friends and with your colleagues and your comrades, for a larger goal for all of us, that’s when it really gets interesting. And that’s when it’s even more fulfilling and powerful.

**RR:** And this creative essence of him really comes through in the way that, even just as an early young man, in envisioning his reaction to the public as his celebrity. As a young guy, I thought that was really remarkable.

**SD:** Yes, and later when he told those stories, he told them very matter-of-factly, like, you know, I just viewed myself as a celebrity because they were staring at me. It’s not that simple. That was hard work, over years, for him to think of himself in that way, under those situations of being stared at.

**RR:** And I like the way you’re describing this trajectory of fighting—first for himself, and then joining a community and making that a larger battle. And I really liked in the book the ways in which we kind of get a real clear sense of where he’s learning this from, and what these elements are—from his mom, from everything happening in Berkeley, from the various movements that are in the atmosphere. And I really liked—also, I didn’t know about his taking karate. What a real surprise to me!

**SD:** If you can… you can look online, if you dig around, you can find a video or two, and it’s just fun to see him. Essentially, he was taught his own self-defense, you know, because he’s not doing your standard karate moves.

But, you know, what can someone in a power wheelchair do? And when you watch some of these videos, you go, ooh, a power wheelchair is a big, heavy… you know, it's quite a weapon if you know what to do with it.

**RR:** Yeah, but that was a real page turner moment. I couldn't wait to see what's on the next page when I heard he was about to start karate. Where are we going? Any other big surprise for you in your research about him?

**SD:** Big surprises. I will tell you a personal piece that came up. Which was that… I knew all along I came from the perspective of being a non-disabled guy, and that in some ways makes me the wrong guy to write the book, I understand that. And otherwise I'm the right guy, because I was willing to do it, I guess. But in the midst of doing this, my son was diagnosed with autism in the 11th grade. Now, it answered many questions for us. And also, you know, I'm supposed to know something about disability, but I'm obviously not a clinician. But so then we're dealing with the special education system and the public schools, and the regional center in California, which is the system of developmental disability services. And so now, as I told a friend of mine, a good friend of mine who has a son with an intellectual disability, I said, I thought you were the father of the disabled kid. And I realized I am too. And it put me in a different position. It just changed my positioning in relation to this. But it also made me realize, too, that a book like this—you know, you think of the readers and the stories—either you have a disability, or you're going to have a disability, or you have a family member or loved one who has a disability. That's our society.

**RR:** Yeah.

**SD:** I mean, everyone has a close connection. They may not admit it, they may not know it, but it's about all of us.

**RR:** Yeah, I always say that disability is only relevant if you have a body.

**SD:** That's a good statement. I'm going to steal that. It's so true, because our bodies are vulnerable, and our bodies don't do what we want them to do, and in the end, they're going to run out on us. But it just changed my perspective on the whole work to realize, oh, this is all of us. It is all of us.

**RR:** It is all of us. And as your book really shows us, everyone's experience of disability is so deeply tied to policy, environment, and all of these things that change what their experience is and their access to a full life, like the one Ed created for himself. Now, Steve Brown—I know he was a central figure, you know, for all of us, for disability studies, and here at University of Hawaii, and for the Review of Disability Studies—how was he involved in the book, before his passing?

**SD:** I knew Steve, I don't even know how—you know how you know people and you don't know how? I knew him just because we're all in the same game. And then I heard that he had interviewed Ed and Zona. One of the problems was that there were lots of interviews already completed. And I conducted many, many interviews, but they really weren't in-depth interviews with Ed, not to the extent that I wanted. There were magazine interviews. But Steve had all these tapes. And he mailed them to me!

**RR:** That's amazing.

**SD:** He just mailed me all the interviews he did, and I listened. It was an incredible resource, just very, very helpful. And then also, to know that he was willing to do that, and that he was behind it—he told me, essentially, that this was what he had wanted to do. He wrote an article for Disability Studies Quarterly, but he really wanted to do what I ended up doing. And so I felt like I was picking up his baton and going forward.

**RR:** That's really neat. He was a big mentor to many of us, including me—he kind of connected me initially to the University of Hawaii. You mentioned a little bit about the impact of this research on changing the way you look at your own life and your own relationship with disability. For folks—what do you think, after all of your research, are the most important things for people to take away? The lessons that we can get from spending time with Ed.

**SD:** I'll tell you what I used to think it was, and then how it's changing more recently. I used to think it was so important to understand why the many kinds of accessibility that exist today—both policies, like 504 and ADA, but also just everything from curb cuts to whatever is available that helps people participate—I wanted to make sure that people understood how those came about, that they didn't just pop up out of nowhere. And it was a long, hard, fascinating road to achieving those, not that that is done. There's obviously a lot more to go, a lot more to be done. But then, more recently, we see a federal government and administration that is unraveling the very achievements of that generation. It's shocking. I always thought the big problem was, can we actually go further? Can we actually create better accessibility? Can we do this more fully and for more people and with greater respect and with much better funding? And now we're seeing that the planks beneath us are being pulled out. It's happening so much and in so many ways, that if you follow the news, it's just very, very upsetting. It's incredible. I don't know what it'll take to even repair the damage, never mind begin to make progress again.

**RR:** What an amazing time for your work to come out, both to bring attention to where these victories came from, and how important they are to keep fighting for, and to see how we can expand them.

**SD:** Well, the book shows how thoughtful the people were. I mean, these were incredible radicals who fought in the streets, but they were brilliant, and they had long, long discussions about every single issue and every single policy. And the people right now who are unraveling and taking it all apart are the opposite. They're not thoughtful. They're like a drunk with a machine gun. They're just letting loose on anything that's decent, and hoping they can take it apart. So it's very much the opposite. But I still am convinced that the way forward is through that kind of thoughtful dialogue and thoughtful solidarity, where people think seriously about what do we need to do, what are our problems, and how can we make lives for everyone better.

**RR:** Yeah, and I was thinking about the way that you kind of brought attention to Ed's trajectory of being acutely aware of your own need, finding ways to address that, banding with community, and then putting your forces out in the world. What a neat lesson he is for that.

**SD:** And I think that's what happened to the original group of students on the Berkeley campus. They had a group of disabled students living, of all places, in a university hospital on campus—not where Ed wanted to be housed, not at the appropriate dormitory. But 1968, '69, that's where they were, and they had these conversations where they all radicalized each other, basically.

They realized the predicaments I have been in are not personal, they are shared with the person I'm speaking to. And the other person across the table—we're all in this situation. Maybe it's the world around us.

**RR:** Yeah…

**SD:** And so, essentially, what we like to call the social model of disability—a politicized understanding—is what a bunch of college kids cooked up in their late-night conversations.

**RR:** And it sounds like they turned that dry hospital into an interesting… fun hangout to be.

**SD:** Well, it was late '60s in Berkeley, so it was fueled by a lot of substances and a lot of good music.

**RR:** It sounds like it. And I know we just have a few minutes, I wanted to ask you, just quickly, your book is published with University of California?

**SD:** Right.

**RR:** Why did you choose them?

**SD:** There's a couple answers. I'll give the highly respectful one. It's just an appropriate publisher, because they're devoted to telling California stories.

**RR:** Yeah.

**SD:** And this is a story about—you know, I tell about Ed going to many, many places in the U.S. and beyond, this was a worldwide movement that he was involved in—but it's also a Berkeley story; it's a *Berkeley Radicals Take on the World* story.

**RR:** Yeah.

**SD:** You know, the shaggy-haired hippies smoking the weed with those weird ideas, they're going to take it to the world. So it is a California story. But, you know, the other version, I will tell you, is the number of places that turned this book down. I'm not going to give you a number, but it's a crazy high number.

**RR:** It sounds like J.K. Rowling. Like every successful book I'm aware of, there's always tons of proposals on the way.

**SD:** Well… so I was thrilled. I was thrilled to find this publisher, and they've treated me well.

**RR:** It sounds like it. If you want to mention anything upcoming that you're working on?

**SD:** Well, actually, from the beginning, people have said, where is the audiobook? Suprise, surprise, surprise—a highly accessible version, like an audiobook, is an afterthought. It doesn't just happen. It can possibly happen later. And my publisher and other publishers who specialize in this did not pick it up for audio, despite the fact that many, many folks in the disability community have been asking from the beginning for an audiobook. And so I arranged to get the rights to the audio version back, and I'm working with a narrator right now—a disabled man living in Berkeley, a radio announcer with a golden voice—and he’s recording it right now, so hopefully very soon we’ll have an audio version available.

**RR:** Well, that’s very exciting.

**SD:** I’m thrilled.

**RR:** Be sure to let me know so we can make sure that we publicize it. And anything else you want to say?

**SD:** I will, yeah. No, that’s it. I’m just excited to talk to you, I’m excited for people to know about it. I hope people read the book. Enjoy it. Enjoy Ed.

**RR:** Yeah, me too. He’s a really good friend of mine now and I’m grateful for you to—not introduce me to, but to make me closer to him—and I can’t wait for others to get to spend time with him, too. And I’m grateful for this time with you, thank you.

**SD:** Thank you, thanks.

**RR:** And I can’t wait to share this with other folk.

**SD:** Yeah, me too. This is great, thank you.

## References

Danforth, S. (2025). *An independent man: Ed Roberts and the fight for disability rights*. University of California Press.