

TRANSCRIPT: Luise Custer/Charlie Tygiel
Interview in 4 segments
Disability Rights Education and Defense Fund (DREDF)
Ed Roberts Campus
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Berkeley, CA 94703
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Segment 1

Well, I'm Luise Custer and I was tremendously, happily married to a brilliant historian who was the consummate partner. We lost him to cancer, but before that happened, we had a whole life together for 26 years and it began with Charlie. Charlie was our first child and he came to us very early on and when he was first born, it looked like everything was quite normal and natural and it wasn't until he was a month old that I looked into his face and realized that something was wrong with his eyes. And it was over the course of the ensuing months and the first years of his life that piece by piece we began to realize that we did not have a fully normal young child, but that we had a young man who had a vision problem, then we discovered he had seizures and then when they did an MRI, we learned that his entire corpus callosum was missing, this would be the 200 million fibers that connect the hemispheres of the brain. He had a smaller left hemisphere and that meant that he was going to be developmentally delayed, though throughout his childhood, he was a marvelously happy child, he was communicative, his language was somewhat simple, somewhat repetitive but it's a delight to have someone who talks to you. And the darkest part of his life began unfolding when his seizures went from being somewhat controllable or seemingly minor to being much more severe. He would -- his right arm would rise, he would freeze up and he could literally collapse backward or forward, stiffened completely. Um, so as he got older, we began the horrible dance with the medications and that dance was not a happy one because no matter what we tried, it didn't work. So eventually we did brain surgery, we took -- part of his brain was removed and we hoped that might help control the seizures but ultimately that didn't do the trick. And then finally, the last thing we tried with the seizures that was outside of the medication realm was to implant a vagus nerve stimulator into his chest and that would then, um send electrical current that we hoped would somehow reduce the seizures, but ultimately none of us thinks that any of these strategies worked. And he's still, at age 29 now, has a really severe seizure disorder, one that has been characterized by some people in San Francisco as being as being one of the most difficult and complex they've seen. So my husband, Jules, and I, put together with enormous help from our regional center, the marvelous what I would call parent-vendored supported living setting and it was in that setting that Charlie was then living in his own home and having a fairly good life. We decided that his seizures were significantly escalating, that I was the person who was rooting to replace the vagus nerve implant battery. He had this device implanted under the skin and the battery had to be replaced and

so we made an appointment, it was an outpatient procedure, we had a fine surgeon, we'd had good communication with the surgeon and we get to the hospital and I can tell that the team, the anesthesiology team is running late. I had been reassured I could go in with Charlie to the staging area with them in case anything went wrong and I went to the desk and asked what was happening, why things were so late, we were already past it and I got a rather brusque answer and all of sudden, in come the anesthesiology team and they whisk Charlie off and I'm being rushed in, having the -- my gown and, you know, cap put on. And by the time I reach the staging area, they have laid Charlie out with his arm extended and they -- they're starting to introduce the needle and at this point, there are five people around him and I'm going, oh my gosh, nobody is holding his arm. And of course in a natural response as they insert the needle, Charlie moves his arm. Tragically at that moment, the anesthesiologist panics, he doesn't turn to me as I was hoping he would, he rushes across the room, grabs something which I'm not even -- cannot identify and the next thing I know, he's filled a syringe with a drug, he has without any commentary, rammed the needle into Charlie's shoulder. And I look and notice that the needle is at a, you know, a 90 degree angle and so I'm, I'm watching Charlie who's now becoming hysterical and I'm crying out what in the world are you doing, what is happening here? It turns out that what happened is Charlie had been injected with a drug called Ketamine, and despite the fact that I was sitting with the physician, he didn't stop to ask if we might not have just taken care of the problem by simply securing Charlie's arm and reinserting the needle. Charlie goes into the surgery, it's a very short procedure, he comes out and in the recovery room, shortly after coming out of the surgery, he begins to seize and he has seizures at three minute intervals that go on for five solid hours. And the whole time his seizing is going on, the -- all the physicians that are attending are very concerned and they start saying that we're going to have to drop Charlie into a Propofol coma which is giving him a drug, Propofol, and sedating him so as to get control of his seizures. And we're saying, no, we were hopeful he'll come out but he didn't so much against our desires but realizing we had the risk of him going into status epilepticus, we agreed that he could be dropped into a Propofol coma. It was not until six days later that Charlie was even able to start walking, this drug we were reassured wasn't going to be a problem and by the time the six days were up, Jules and I looked at each other and said this is ridiculous, they're not able to do anything for him, we can take care of him at home. But we went home with the clear knowledge that something very unfortunate had happened and that it likely was the drug that Charlie had been injected with. We then went back to the surgeon, talked to a few other neurologists and specialists and there was pretty universal agreement that the drug Ketamine had caused our Charlie to drop into hours of seizing. For me, this was a tragic commentary on a failed opportunity on the part of the surgeon to have included me, the advocate, the mother by simply turning to me when Charlie moved his arm and asking, what do you think mom, do you think maybe we can just -- what would you suggest? Because he didn't do this, we had one of the hardest two week periods of our lives. It was another entire week before Charlie recovered. I was so distraught by what had happened and

so concerned about those who would come after us and other families that I went and had a long discussion with the anesthesiologist about what had happened. And I urged him to take this situation and make an attempt to address what had happened and set up protocols that would try to avoid that this sort of thing happened again. It is a sad truth that these physicians -- I think he was so startled by what happened with Charlie, Charlie was getting anxious when he was, you know, his arm was -- he didn't -- it wasn't working and the doctor was literally, I think I can say, terrified. And in that terror, had not been trained in such way to calm himself, to step back for a moment to look at me and say, I need your advice. I think the saddest commentary is that with families with disabilities and disabled patients, physicians don't often enough understand how collaboratively we need to work because those of us who have lived with this disabled young person have the most experience, have the biggest -- the greatest insights into what will work and won't work and here was a tragic example. I desperately wish that I could have had some time with the anesthesiologist beforehand to have said to him, instead of answering his questions about Charlie's medical list, to have said to him, I need to tell you that when we go into the staging area, if anything happens, it would be of great import to me that you would turn to me first as a resource that you have. Without that, we had a tragedy on our hands and I honestly believe that these kinds of incidents, when they happen, as they often do with severely disabled young people, especially with developmental delays and seizure disorders, that cumulatively you have a loss of functioning and I would actually say that Charlie who is now 29, has a less functional life by far because of failed medical interventions or drugs that he was given that caused an adverse effect.

Segment 2

There was a period at the end of my husband's life -- he had a rare cancer and he was not well, and I got a phone call that Charlie hadn't been feeling well for several days. And Charlie is unable to discuss when he's not feeling well. He can break a limb and no one will know until it begins to swell. When I asked the staff what they thought was going on and how Charlie was manifesting himself physically, they said that he was leaning forward as if his stomach was hurting him. And I immediately began to suspect appendicitis and this was already several days after he was unwell. I immediately asked them to go in and get a white cell count, which they did, and why they did not do that, "Stat," which would have meant that the results would have been rushed to the physician, they just did a regular blood test. And later in that evening, we learned that he had a high white cell count. I then knew -- I was not with Charlie. I had to be with my husband at that particular point and I told the staff that I wanted them immediately to have this addressed. But it turned out that the physicians wanted a CAT scan before anything further was done and they waited until the following day for the CAT scan. So when Charlie finally got the CAT scan, it was revealed he had appendicitis. They rushed him into the surgery at 8:00 at night, but we are

now four days into the infection setting off. And he has the surgery; it seems that the surgery goes well. He's actually in the hospital for nine entire days which is very demanding [chuckle] and at the very end, the day -- just the evening relate -- the evening before Charlie was to be discharged, I happened to be in his room when a nurse was about to give him several medications and I asked, "What is it you're giving him?" And she said, "Oh, these are two antibiotics that he needs." And I said, "I need to talk to the surgeon. That's -- those -- that's two -- two more drugs in his regimen. I have to be sure that he has checked that these drugs are not going to be problematic with his seizure disorder or interacting with this current drug regimen." I called the physician and he was very dismissive. He said to me, "Well, [chuckle], he had -- you know, he had an infection. This -- he -- we require very strong drugs." I said, "But have you vetted these drugs for interactions?" "Well, you know, he needs these drugs. He has to have them." I was not the least bit happy but I -- he'd had peritonitis meaning he had this infection and so I accepted it. Two days later, Charlie is discharged. He's at home and he begins to have seizures. Charlie seizes on and off throughout the days for almost two entire weeks. We opted to not immediately send him back into the hospital and get Dilantin. We were hoping to keep him out of the hospital. We didn't want -- we wanted to try some other alternatives that the neurologist had suggested, Ativan. But the Ativan just knocked Charlie out and did not give him what he needed in order to control the seizures. It wasn't until virtually two weeks later that we get a phone call from Charlie's lead staff who says, "He's going to be in the hospital tonight if we don't do something." And it was my husband -- neither of his neurologists, but my dying husband who looked up and said, "I have an idea. Let's give him a load dose of oral Dilantin and then put him on just a maintenance dose." We called, arranged for that. We had already been in touch with the on-call physicians. It was nighttime. They agreed to do it and lo and behold, it stopped the seizures in -- in their tracks. But it was an absolute dance with the devil that we had made, almost a pact, because by agreeing to use Dilantin, a drug that we knew was not good for Charlie in the long-term. We had used it in the past to try and control seizures but it led to serious behavioral issues. So we start out, where delirious seizures had start -- stopped. He has a good first month, in fact a very good first month. Seizures are way down, but the second month, he's starting to have more behavioral issues. By the time three months have passed, my husband has now died, I get a phone call the day after my husband's memorial that's telling me that Charlie has gone into hyper-space. He's tipping over tables; he's pulling over books from the bookshelves. They're going to send him up to San Francisco and he's going to have to be admitted to the hospital. What unfolds is -- is a tale of such sadness it's hard to recount because I spend one night in the hospital with five different drugs being thrown at Charlie to try to get these behaviors under control. Nothing is working. Finally, they give him Valium. I'm then told that the hospital cannot provide services to Charlie. They don't have the behavioral setting he needs. We decide that he needs to go to another hospital so we send him to another of the most prestigious hospitals in the Bay Area and while he's there, Charlie is misedicated three times, not on any other drugs but on his own medications.

As the -- as the nursing staff is about to give Charlie his drugs, my staff looks and says, "Wait a minute, that's not right." You know, I have a theory about why Charlie was mismedicated with his own drugs. My staff reported that this Psych Unit, the staff was wholly unprepared to deal with a severely disabled young man. They were not used to having a young man with seizures. They were not used to having someone who could not himself articulate what his issues were. He was reliant on his staff and my staff reported that the nursing team that worked with Charlie there, actually showed that they weren't comfortable being near him. They weren't comfortable addressing him and they most certainly weren't comfortable talking about what his real needs were. So that when it came to administering his own meds, there was almost -- I would say a blocked soul and a mind that was not predisposed to -- to taking Charlie's deepest needs. They wanted Charlie probably to not be on their ward. And in the course of blocking their openness to him, they allowed themselves to do something that was absolutely unprofessional and unethical to mismedicating a patient more than once. Fortunately, if my staff had not been there, you cannot imagine what would have happened if Charlie had not gotten enough of or too much of the multitude of anti-convulsant drugs and behavior meds that he was on. I immediately pulled him from that hospital. We have him at home down in Santa Cruz. He's a wild bit of an animal and my regional center caseworker comes to me and says, "Charlie must now be sent to what is called a dual-diagnosis setting." This is a setting to which people with genetic developmental delays who also have a psychiatric diagnosis are brought. And the only one that's available is not in the Bay Area, not in Northern California, but seven hours away in -- near Los Angeles. Charlie and I are driven in the dead of night in a limousine down to the hospital in Southern California. That is in the end not a hospital at all, but really a psychiatric unit where he is left for the sole purpose of taking him off the Dilantin because we realize now that in a very paradoxical way, the Dilantin has so suppressed Charlie's seizures that the seizure activity, what we call sub clinical seizures, is so fierce that he is going quietly mad. The agreement with the psychiatrists at the institution that we've taken him to is completely clear. "We want some seizures. We are taking Charlie's Dilantin down and that is what is going to bring him back to stability and allow him to go back home." Ten days into his stay at the institution, Charlie has a 30-second seizure, which in our universe [chuckle] is a virtual non-seizure and I get a phone call that an internist at the setting has immediately taken the liberty of raising Charlie's Dilantin, not titrating it, but taking it immediately right back up to the level at which he came into the institution and this is end game. They will not allow any seizures. So we have a complete disconnect between the psychiatrist who made the agreement with us, and the internist who's decided we can't have any seizures in this setting. We have a -- a few days later, a round-table discussion with every one of the team there and my caseworker's on speakerphone. We're as much as told that Charlie's okay now, he can go home even though he's still at the level of Dilantin he was on and the staff, when I say, "That's great, we'll take Charlie home," I hear from my staff on the speaker phone at this meeting, "Louise, we can't bring him home. We're not ready to take home someone who is in as much extremist as Charlie is." His

behaviors have calmed some but he was not at all ready to be in a safe setting at home. So for another two and -- two weeks, Charlie at \$1,250 dollars a day, is kept in this institution getting none of the treatment he needs and none of the reduction of the Dilantin that is going to bring him back to a normal level. This is the crisis that we're facing here in California. We do not have adequate dual-diagnosis crisis centers for our adults and young people. When this incident occurred, it became clear we needed another option. When I made investigations to see what other options there were, the only suggestion that was made that Charlie -- was that Charlie would go to a developmental center and that if he were in crisis again, his need would be taken care of there. We did all that was necessary to get him set up there for a future crisis, only to learn two years later that due to the funding cuts, the Sonoma Developmental Center would not be able to help Charlie and there was no option there. I did extensive research in the State of California to -- to identify other dual-diagnosis crisis settings. There was only one and when we went to apply to -- this is other than the inst -- the setting in -- in LA, when I went to -- when we went to apply to have Charlie considered there, we suddenly got word that that institution was not able to take any more referrals because there had been some problems there. They had been cited and all referrals were now stopped.

Segment 3

Charlie has a marvelous house that looks out on the Monterey Bay in the little community of Aptos, which is just south of Santa Cruz and in this setting he has living with him two young women and the lead staff. We're lucky enough to have a space for the lead staff that's separate so that he has some privacy. During the days during the week, Charlie is at his remarkable Camp Hill Communities California, which is this marvelous village with fairly high functioning young people. There's a range of disability, but they're all living together in two beautiful houses. They're living actually I think the address would be in Soquel which is just a bit north of Aptos and in the morning Charlie is taken by car up to his Camp Hill setting. Camp Hill has a very profound connection to the arts and to biodynamic farming, to a very humanistic approach, to life, both educationally and socially.

This is your friend Caesar.

We're both wearing blue just like [inaudible]. Yeah and you got purple but I got red. I got green pants, green just like [inaudible]. Yeah. We're going to shoot some hoops.

Like Barry Bonds.

Like Barry Bonds, I think more like Michael Jordan.

That's right.

There it is. [Cheer]

There it is.

I got it.

Good job.

I got it.

Should we draw another line?

[inaudible] line.

Ok

[inaudible] doing.

Claudia he's writing your name. First a C and an L. Claudia he wrote your name.

Oh my gosh. I wrote my name.

You wrote it.

I really wrote it.

Good job.

Yeah.

Charlie is graced to have the most community orientated based life that you could possibly imagine.

Segment 4

I think we need to train our physicians, our young physicians coming up through medical school, there have to be courses. I had the privilege of being invited to speak to the nursing school at a hospital here in San Francisco, I was with another group of parents and there were nursing students there and my expertise was valued immensely in that two hour session. We need to have every young medical student, every young nursing student who goes through the system educated with serious coursework. It's important to have on the exams that license and certify these new physicians, questions that actually show the insights they've gained and the expertise they've garnered by being exposed to parents, disabled young people, advocates and the work that a lot of the

agencies are doing so that these medical students have a much broader sense of how at risk these patients are and how the quality of the medical care that they can provide is going to be wholly determined by their learning early on that this is a very different population and requires a much more collaborative approach. I think many physicians do not understand, many psychiatrists do not appreciate this complex interaction of the behavioral and the medical, the side effects from the multitude of drugs that our people are taking, that one drug that causes a reaction that you didn't anticipate. So you've got people who don't necessarily have a psychiatric diagnosis and those that do have a diagnosis with nowhere to go when they go into crisis. My ardent plea to the policy makers, to the physicians, to the advocacy community is that we need to work together to create more settings into which you can bring our complex seizure ridden young people when they have a behavioral breakdown. And today if Charlie has one of these breakdowns, he will have to be treated at home, we will have to hire nursing staff, we will have to rely on the neurologists and the physicians that are in the wings but we're going to be -- forgive me -- flying by the seat of our pants in a very dangerous setting because no hospital will take my son for longer than a few days to simply stabilize him in the short term for the whole trajectory for as many weeks as it takes to bring him back to baseline, that will be on our heads and that is not a safe situation. Of all the issues in the medical arena that concern me, it is perhaps the failure to correctly diagnose what's going on and have specialists who can address this thoughtfully and accurately. We also just need much more cultural literacy that everyone who works with our community somehow learns from the heart, as well as from the mind, how to understand the simple needs that go unattended. The anesthesiologist wishes he hadn't done what he did but he panicked because he was afraid of Charlie, he was afraid of the situation, he was afraid of my concern and those fears stand in the way of creating this cultural connection and understand that then will bring a better diagnosis, bring quicker management of serious problems.