

TRANSCRIPT: Aaron Reetz, Gordon Reetz, Susan Lee, Dr. Clarissa Kripke
Interview in 5 segments
Disability Rights Education and Defense Fund (DREDF)
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Segment 1

I'm Gordon Reetz. I'm Aaron Reetz's father. I'm a retired employee from the National Park Service. I was a biologist for the National Park Service and I worked in the wine industry after retirement for a few years up until when Aaron started to live with us. And, uh, we live in San Francisco.

I'm Susan Lee. Gordon and I have been married for 26 years. So I've been Aaron's stepmother for basically 28 years since he was about 4.

Gordon: Aaron was born in 1979. He's 33 years old. He was born premature. We were -- we suspected everything was okay except for him being a very small child, of course but then a day after he was born, he had a hernia operation and then coincidentally he developed problems and having seizures and kind of constantly crying for years from then on. He is -- at one time was diagnosed as having cerebral palsy. Some -- prior to Dr. Kripke he was -- thought he was somewhat autistic.

I'm Dr. Clarissa Kripke. I'm on the clinical faculty at the University of California San Francisco in the Department of Family and Community Medicine. And I'm the Director of Developmental Primary Care.

Gordon: I believe it was in August of 2008, went away for the weekend, came back, and there was 4 messages on our answering machine. My ex-wife was diagnosed with early onset Alzheimer's and that the social worker took Aaron away from her because of the care he was receiving with her. And he was in the hospital trying to get to a stage where they could release him and he was and they were going to release him that Monday. So I got the call Sunday night and Monday I was up at Sacramento to pick him up and brought him home and then we thought now what?

Susan: This call was a complete shock to us. That and apparently her -- they were in Sacramento. We're in San Francisco. So they were about 100 miles away and her family, the ex-wife's family, had known that she was becoming more ill but nobody had told us anything. So between Sunday night and Monday noon, Aaron came to live with us full-time and we haven't seen him for a year although he had spent, you know, good parts of years with us in earlier times. We were unable to get any medical records at all because whatever she had had disappeared into the sort of chaos of her life and her immediate family didn't know who had been seeing him. So Gordon and I are both patients at UCSF Family Medicine. So we called the clinic at Lakeshore and said, "We have a new member of our

family living with us. Can we bring him in?" just to the receptionist. And they said, "Oh, sorry everybody's full," and we went, "Oh my God." We had no idea of where to go from there. When we heard from Dr. Kripke, turns out she has this amazing relevant specialty in exactly what we needed for Aaron. She ended up calling us back from an email that was sent. I don't know to who. I know it wasn't to her but it ended up back at her calling us when we were picking him up from a daycare situation and talking to me, I think, initially on the phone because Gordon was driving for probably an hour understanding his situation. And then a day or two later came to our house and did a whole medical exam with Aaron for 3 or 4 hours. And that was shocking to us and wonderful. We were, you know, terrified. We didn't know how to -- you know where to begin.

Dr. Kripke: I'm also the parent of a 10-year-old autistic child and I got interested in working with adults with developmental disabilities because people were showing up in my office and I couldn't serve them well in 15 minute appointments. So people were coming to my office and I said to them, why don't I come to you? It'd be a lot of better if we did this in your home and started doing work with people in group homes and it -- my interests built from there.

Segment 2

Dr. Kripke: Well Aaron's part of a new generation of people with developmental disabilities who have thrived as children with all the services that we put into place since the 1970s and who have done so well that they've reached adulthood and are outliving their parents' ability to continue to care for them. And so we have done a great job of developing healthcare services for children and we just haven't developed the capacity of the healthcare system to care for adults when they age out of that system. With a new patient with a developmental disability, they all have complex lives and it's very helpful to do a home visit especially for a first visit because people are more calm and able to communicate, because people are -- because you're able to meet with more family members and relevant people because you're able to see their environment, which is very important for assessing what kind of equipment and what kind of skills they might have. Because people, all of us, behave fairly atypically when we're in a doctor's office so the most -- some of the most important things that I do when I meet a new patient are to get to know who they are. What's their baseline? Who--What are the patient's communication skills? What are their cognitive skills? What are their ability to move, their neuromuscular skills? Do they have vision? Do they have hearing? Do they have sensory integration challenges or differences? And do they have any mental health behavior or seizures? So it takes -- I do a very detailed functional assessment to look at all those different areas because illness tends to present as a change in behavior or function and if you don't know what someone was like before then you don't know what's changed. And if you don't know who somebody is in all of those domains, then it's harder to predict what kinds of services and supports and equipment will help them to maximize their potential. It really helps to have enough experience working with people with developmental disabilities to know what types of things are common and what kinds of problems people have so that you can ask good questions. And I'll tell a little story about Aaron's communication. Like you say, he doesn't use words to speak very often but every time he comes in, I ask about whether he's

in pain because I expect that over time because of his gait that eventually he's going to get arthritis in his legs and knees. And so one time I asked the caregivers if they thought he was in pain and they said no. And then I inquired a little bit further, "Well, how do you know?" And they said, "Well, because he's not making the grimaces and holding the part that hurts and doing the typical kinds of behaviors that people do when they're in pain." And I said, "Well, but he's autistic and so maybe he has some differences in how he perceives pain in his body or how he expresses it." And the caregiver said, "Well now that you mentioned it, he really loves going on walks but lately he hasn't been wanting to go on his walks." And I said, "Oh, that's a change in behavior." Why don't we just try some pain medicine and see what happens and we gave him just some simple Tylenol and he started to want to go on his walks again. So he was able to tell us when something was wrong if we were supporting him by asking the right questions.

Susan: And Aaron's vision has always been an issue because he had when he was about 5, he had cataract surgery and he had his lenses removed. And he -- it was eye opening to all of us at the time his -- the day of his surgery he was given glasses. They did it one eye time at a time and he wouldn't take them off after that and he was very small not communicating at all but he loved his glasses. So it was very clear that he was seeing much better for the first time and he's been like that for 35 years.

Dr. Kripke: I'm so happy that we've been able to work with a specialist to preserve Aaron's vision because you can see how much he enjoys those books. And that's one of the first things that I noticed when I first came to your home.

Segment 3

Gordon: Well after we had our first visit with Dr. Kripke, we had -- the assignment was to get -- to take Aaron to a number of different specialists.

Dr. Kripke: There are very limited resources in terms of specialists who have particular interest and skill in working with adults with disabilities in general and a lot of referral resources are determined by someone's health insurance and their family's ability to navigate those complex bureaucracies to get access to the few specialists who do have some skill and experience. I gave referrals to the best people I know but they aren't necessarily people who have received any training. They aren't necessarily people who have a special interest or special funding to do the work and so there's very limited ability for them to do it on the scale that's needed.

Susan: The dental thing was a challenge. I mean it took a long time. I don't -- I think it was 6 months or a year before we actually got an appointment with Aaron to see a dentist because when he goes to a dentist, he won't open his mouth. So they needed to deal with his teeth, with a general anesthesia and that's not a common dental thing.

Gordon: I think it was Dr. Kripke that said we got something through UCSF or maybe it was Regional Center that they were able to take him in and that was a straight forward process.

I signed a few papers and he went in as an outpatient and came out that afternoon. And with -- his first in our experience, dental exam or dental treatment.

Dr. Kripke: In terms of specialty needs for people with developmental disabilities, I think dental and mental health are the two specialties that are the most specialized in terms of the knowledge base and expertise of the specialists. There is very, very, very limited access to special needs dentistry in the Bay Area. There are a couple of programs, one at UCSF, at the University of the Pacific, and at Seton Hospital. And the funding for those special programs doesn't come through the regular systems but is supplemented through the Regional Center and not all patients who are Regional Center clients have access to those special dental services. There are some very wonderfully novel ways of delivering quality dental care to people with developmental disabilities through homecare models where dental hygienists who have advanced training can go into homes and they can use video cameras and mobile x-ray equipment to do a lot of the care in the home and a lot of people are so much more comfortable when they're around their familiar surroundings and with their usual caregivers. And when people aren't under such time pressure because there are people waiting in the waiting room for you so you can be more patient as you provide the care and so that people can have enough patients in their practice to develop comfort and skills in working with people who maybe communicate in different ways and nontraditional ways or who have special sensory issues with getting the care. So it's always a challenge to access dental care and 6 months is actually quite quick for most people to achieve care and that's because of your tremendous advocacy. I'm going to take a risk and tell you a story about my own incompetence. When I first started doing this work, I was going into group homes and in those group homes, I met many people who had very poor dentition. Most of the people who lived in those homes had once lived in institutions and had moved out of them. And many of them had no teeth at all and those that did, had very severe dental decay and plaque. And the dental hygiene was quite poor. And I actually thought, embarrassingly enough, that that was a part of the disability -- that having odor in the mouth was part of what necessarily had to happen but then the Regional Center did a special project where they went out into the group homes and did some education. We ordered water, water picks, and suction machines and special toothbrushes that have adaptations on them and chlorhexidine washes and other types of sprays, Xylitol spray and we really worked with the caregivers and each individual to figure out what regimen would work best for them, for just general preventive care. And after that, the number of the people who had medical problems, not surprisingly related to their dental care, went way down.

Segment 4

Dr. Kripke: What we're talking about is really developing a new field of medicine, there really isn't a board certification or training program in developmental medicine or developmental primary care, those are -- the few people that are working in this area are self-taught based on their own interest and initiative and most don't actually have any special funding. So it's very limited -- our capacity to provide the services to everybody is quite limited. Over the last 40 years, we've done an amazing thing, which is most people with complex disabilities, developmental disabilities, lived in institutions 40 years ago and

we have done an amazing thing to close almost all of the institutions and the few that are, that are still open are in the process of closing and to develop good lives for people in the community. Forty years ago, the life expectancy of people with developmental disabilities was quite limited, there were very few people that were living long enough to outlive their parent's ability to advocate for them. So we knew we needed to develop special education, we knew we needed to develop developmental pediatricians and specialty, specialty services for kids but we really weren't thinking in terms of people benefitting from those resources and living longer lives. But now we have a whole generation of people who have thrived as children, who have developed skills in special education, who have vocational skills who want to work, who want to participate in their communities and who want to enjoy themselves. And we don't have a system in which -- a healthcare system for them to graduate to. The Office of Developmental Primary Care at UCSF was established to help improve the capacity of the healthcare system to serve the population of transition age youth and adults with developmental disabilities. The model that -- the components of a comprehensive model of care for this population includes the CART Model, which stands for -- C is for cart -- is for clinical services which is both special primary care and specialty services. The A is for advocacy, both advocacy to support patients to partner effectively with their healthcare professionals and policy advocacy. And the R is for research, which is research in health services delivery and health policy and clinical research, uh, not so much research on cures or prevention or etiology. And the T is about training and technical assistance for health professionals, caregivers and for self-advocates. So the CART Model is a comprehensive system of care that's organized around the patient and the components of it include a primary care office that has additional resources and time to develop expertise and office procedures or homecare procedures that work for people with more complex disabilities. There are health advocacy services, which are the direct support services for patients who need help to follow through on doctor's recommendations, to provide a history or to advocate for themselves, to make informed consent decisions. Then there is a center of excellence in developmental primary care, which is where the research and the policy advocacy work can be done and much of the training work that can be done. And then the fourth component of the model is comprehensive health assessment and that can be done by a trained nurse who does it as a homecare model, much like the first visit that we did in your home, because if we are not proactive, if we just wait for patients to come to us and say they have a problem, that may never happen and that was part of what I think is illustrative about Aaron's story is that Aaron and his mother were not able to come to the healthcare system and ask for help when they needed it, we had to go to them and say how are you doing and assess how you're doing and make sure that all of his medical needs and his mother's medical needs were recognized and met. We need that proactive piece of the puzzle that isn't there for most people who can access healthcare when they know they need it. And I'm hoping the healthcare reform bill and some of the innovations that are coming out of that will lead us in that direction but it's going to take a lot of advocacy.

Segment 5

Gordon: I really can't imagine somebody going out without a doctor that has such care and dedication, and long hours of work to do what she's done. And it's -- I wish them well, finding a doctor like Doctor Kripke, but that's been our great fortune.

Dr. Kripke: I really appreciate your kind words. There have been policy papers written by every major organization -- the National Council on Disability, the Institute of Medicine, the Centers for Disease Control, the World Health Organization, the Surgeon General about healthcare for people with disabilities and people with developmental disabilities, and they all come to the same conclusion, which is that we need to train healthcare providers. The major barrier to making that happen is funding, not just for the training and for teaching clinics, but funding for people to do the work, because we can't develop training programs if people can't make a living with the current healthcare finance systems.

Susan: He has not been this healthy consistently, ever in his life, in terms of colds and falls, and stitches, and [laughter] just all the things that, you know, to some extent all the things that kids have when he was littler, but certainly him since his balance is not great. This past few years have been the healthiest time of his whole life. So it's definitely been good for him, the combination of Doctor Kripke and his living situation, where there's a lot of interaction and very much eyes on. And so it's been great.