You First Podcast Episode 56: Willowbrook and the Future of Disability Rights

Maddie Crowley (00:00:00):

You're listening to You First, the Disability Rights Florida Podcast. In this episode, we talk with Dr. Bill Bronston and the National Disability Rights Network's executive director, Marlene Sallo, about the Willowbrook State School, its expose and its impact on the Disability Rights Movement. Hi, everyone. I'm Maddie.

Keith Casebonne (00:00:36):

And I'm Keith, and we're the host of You First. This episode intro is going to be a bit longer than usual, so we ask you to stick with us for a few minutes because we just have a great, very powerful episode for you today. We're going to be talking about the Willowbrook State School that was in Staten Island, New York and was open from 1947 to 1987. And as our guests will explain, this was far from a school, or honestly, a place that you would really want anyone to live. What it really was was a segregated institution where people with disabilities were warehoused away from society. And as this brief intro on Willowbrook alludes to, this episode is going to get heavy and does talk about some very heavy but very important history and current issues.

Maddie Crowley (00:01:28):

Yeah, definitely. And before we get into the episode further, just as a more thorough content note, this episode is going to include strong language, explicit mentions, violence against and death of disabled folks, institutionalization, medical trauma and eugenics, so please go into this episode with that in mind. But like Keith said, it is such an important and unfortunately not well-known story and history, and present day history, but we'll get into that.

(00:02:02):

But it really needs to be better known, especially as we have calls, both past but currently very present, from political leaders to bring back institutions, to forcibly evaluate students in schools as having psychiatric disabilities, to remove unhoused people from their living situations, whether that's on the street or otherwise. And that's all without a robust and supportive network of community-based services for these folks, and this episode really helps highlight how incredibly dangerous it is, how we rely on institutional and carceral systems in our country and something we should be really mindful of, and just invites us to remember our history and tell what I can describe as nothing else than just the absolutely harrowing and visceral and insidious story about how all of this comes to a head.

Keith Casebonne (00:03:08):

Yeah, you couldn't have said it better, Maddie. It's a dark story and time in our past, and the last thing we want to see is this coming back again. This is not the history we want to see repeated. But also keeping all that in mind, we really didn't edit much of the content of this episode. Maddie, we both feel strongly that we don't have the authority to police the language used in this episode or should take any parts out, because each instance has helped us, and hopefully will for you as well, to frame the level of violence that took place. We really hope that listeners keep that in mind as you may hear language that you do or don't agree with, that we are trying to do right by the thousands of

people who died in Willowbrook and across institutions in America by leaving in some pretty emotional and strong language that we hope adequately conveys the magnitude of the problem.

Maddie Crowley (00:04:04):

Yeah. We both really believe, like I have already mentioned, that this is an important history for us all to learn, but I get emotional in the conversation or just listening to this, but everybody should know about this, especially if you live in the United States and specifically for folks who work with people with disabilities and those within the healthcare field. This history that's mentioned in the story of Willowbrook and institutionalized America really shapes how we perceive and understand disability as a concept, as an identity, all of those things today. And this episode, Dr. Bronson's book and the history of Willowbrook really is an important resource that we all need to lean on to understand where we are today.

Keith Casebonne (00:04:57):

Yeah, so true. And one last note before we get into the introductions. With all that in mind again, not all of the words and views of the guests necessarily equate to the views and opinions of Disability Rights Florida. Now that that's settled, out of the way, let us briefly go over two incredible guests we have coming up.

(00:05:18):

So first up on the episode is Dr. Bill Bronston. William Bronston was born and educated in Los Angeles, California, received his medical degree at the University of Southern California School of Medicine, and completed his residency in psychiatry at Menninger's School of Psychiatry in Topeka, Kansas. While he was a senior in medical school, he founded the Student Health Organization in 1964, which was dedicated to promoting universal healthcare as a human right. He was a leader in a range of human rights and labor issues in the healthcare field in New York. Deeply concerned about the plight of children with developmental disabilities while in New York, Bronson spent three years as a staff physician in the infamous Willowbrook State School in Staten Island.

(00:06:04):

As a public advocate, he helped architect the 1971 federal class action lawsuit against New York State for constitutional violations of due process, right to treatment and freedom from cruel and unusual punishment that aimed to close and replace its state institutions with individualized family and community services. He served as the senior consultant to the director of the California State Health Department, a medical consultant to the Secretary of Health and Welfare, and finally, as medical director to the State Department of Rehabilitation where he served till retirement in 2006.

(00:06:38):

He then organized project interdependence that helped hundreds of multicultural teen youth with and without disabilities toward career futures in the fields of science, sports, recreation, and the arts. Finally, he has recently returned to his central and lifelong devotion of organizing, for United States and California, healthcare as a right. Bronson again became a major voice in the Physicians for a National Health program, 30,000 strong, nationwide, progressive physician organization which is dedicated to advancing expanded Medicare for all single payer healthcare in America. A very busy man. A very accomplished and very wise man.

Maddie Crowley (00:07:21):

Yeah. And after we hear from Dr. Bronston, we'll hear from Marlene Sallo. So Marlene is the first woman, first Latina, and first person with a disability to lead the National Disability Rights Network or NDRN. She believes amplifying where disability intersects with other identities such as the LGBTQIA community, non-native English speakers, BIPOC, Black, Indigenous, and people of color, all of these intersecting identities is really critical in disability advocacy and successful advocacy. Before joining NDRN, Sallo served as the director of preventing targeted violence at the McCain Institute for International Leadership. She previously served for almost four years as the executive director of the Massachusetts Disability Law Center, the Federally Designated Protection Advocacy Agency for the Commonwealth of Massachusetts. And earlier in her career, Sallo was an education attorney with Disability Rights Florida.

Keith Casebonne (00:08:21):

Hey, that's us.

Maddie Crowley (00:08:23):

Providing protection and advocacy to students with disabilities and children in the state's Child Welfare System. Sallo was appointed by President Barack Obama to serve as the staff director of the US Commission on Civil Rights in 2013, and she later worked for the Obama Administration at the US Department of Justice Community Relations Service as the chief of staff and senior counsel. Sallo has a BA from Manhattanville College and a Juris Doctorate from Florida State University.

(00:08:50):

So without further ado, with these awesome guests, please settle in for our episode, Willowbrook and the Future of Disability Rights. Hello, Dr. Bronston. Thank you so much for being on our show today. Could you take a few moments to tell us a little bit about yourself?

Dr. William Bronston (00:09:08):

Well, Madeline, my name is William Bronston. I'm a physician. I'm 84, much to my chagrin, and I live here in northern California in the state capital in Sacramento. I was essentially raised in Hollywood and Beverly Hills, so my family were very involved, my father was very involved in movie making when I was growing up and I decided that I wanted to be a physician and not have anything to do with the film industry. I went to Hollywood High School, I went to UCLA for my undergrad, and essentially emphasized a pre-med and 20th century history. I followed that up at USC School of Medicine where I graduated with my medical degree, and then spent a year at Children's Hospital of Los Angeles doing a straight pediatrics internship.

(00:09:58):

And then because of the draft and the Vietnam War at that time, I was a conscientious objector and I wanted to essentially not serve the war effort in any way. And so I got my CO and I had to choose a place to do two years of alternative military service. I went to Menninger's School of Psychiatry. I organized an American Federation of State County Municipal Employee Union there, and as a result, instead of striking the hospital when we had to somehow force the administration to provide adequate wages and a meaningful work situation, we seized all the hospitals in eastern Kansas instead of striking healthcare services. I was essentially fired from that job after two years because of that action, and I went to New York.

(00:10:52):

I spent a decade in New York, and the main job that I had there was at Willowbrook State School because I had profound training at Children's Hospital in child development. My mentor there was a fellow by the name of Richard Koch, who was really the founder of the Association of Retarded Citizens and the Down Syndrome Congress as a result of his work, and so I was raised in an extraordinary environment of child development, technology and service in a most beautiful way. And the whole campaign of Children's Hospital was to deflect people from institutionalization, from congregate segregated housing because they were different.

(00:11:34):

At that time, the medical community was essentially guiding all parents to essentially put their kids, if they had a disability label, into institutions, and the parent had to make a decision whether to hold on to their child, their new child, or to put them away and try again, which was the mantra of the medical community, as if this was a terrible mistake and that there was no way of nurturing or caring for that child. So when I got to Willowbrook, I was absolutely astounded at the magnitude of dishevelment and barrenness that I encountered, and the enormity, the clinical responsibility as a ward physician that I was assigned to address.

(00:12:33):

I was put into a complex of five buildings called the baby buildings euphemistically, and my building had four major wards in the building, two floors, and each ward had 50 terribly broken young people, children. I had three nurses all together. There were two workers per ward, eight workers, three nurses and myself, and so here I was looking at 200 of the most severely disabled young people that I had ever seen in one place at one time, and the records were absolutely barren. Each of the records were inches thick, but they had no meaningful information in them. They had no meaningful diagnosis, they had no medical clinical follow-up notes in terms of what was happening with that youngster while they were at the institution. Many of them were admitted sometime between the ages of three and five years old roughly, and now most of these kids were roughly between five and 15 years old.

(00:13:47):

There was no meaningful furniture anywhere in the building. The floors were terrazzo stone. The echoing, the noise, the smell was incredible. The children were strewn during the day on mats on the floor with tremendous spastic contractures. There was no programming whatsoever going on. My ward workers had no training whatsoever in child development. The nurses were there in order to administer medications and take care of a variety of mechanical issues with the residents in the building, and I was just thunderstruck. I'd never seen... I mean, when I was at Children's, there were 200 beds at Children's and 400 of the top physicians in the country, pediatric physicians and specialists. And my relationship with Dr. Koch, with Richard Koch was that he was serving families in order to deflect them from being institutionalized here in California and to provide services to the families to maintain their youngsters if they had special needs in their home without being institutionalized.

(00:15:02):

And he had at his fingertips, at any moment, access to 400 of the top specialists in pediatric medicine imaginable. In metabolic gene technology, hearing speech, you name it, everything. And I just grew up with that paradigm, that experience. So when I got to Willowbrook, and there I was essentially by myself with 200 kids that were just incredibly anonymous, I had to learn their names. Their families were not there. The ward workers were mechanically driven in terms of managing that volume of life. The nurse was rigid and not particularly clinically capable, and so that's how it

began. That's how I wound up in Willowbrook, and I was moved profoundly. I was overwhelmed and I had no idea how I was going to engineer managing that number of kids and what the goal was, because it didn't seem to me that there was an exit.

Maddie Crowley (00:16:09):

And in your book, once you talk about getting into the lawsuit and the investigations of staffing and the amount of time that some of the care and things, how much it takes, even to do the basic medical and sanitary, dispersing medicine and clothing, bathing and eating, there quite literally wasn't enough time for the ward staffers to even do that you found in some of... One of your nurses did a work study based on the expectation that they had to work. So it's no wonder that this place not only didn't live up to basic human standards of feeding and eating and being clean, but that unfortunately, a lot of medical malpractice, medical experimentation and injury happened.

(00:17:07):

You opened the book talking about one young girl, her name's Lillian, and you use her case and use her story to open up the conversation about just one person's experience of living in Willowbrook. And I think what's so powerful that you talk about consistently in your book and just in telling the story of Willowbrook, is that this is one person out of the many people that live at Willowbrook, and there's hundreds.

Dr. William Bronston (00:17:43):

It's about 6,000.

Maddie Crowley (00:17:43):

Yeah, 6,000, incredibly overcrowded, but that there's 6,000 Lillians. Each person has an experience like no other. So I was curious if you could speak a little bit more to that and how, beyond the basic sanitation and inability of staff to just provide basic care, how some of the realities showed up for people like Lillian when they would go to try to seek serious medical care and just be denied that care by the emergency clinic hospital physicians.

Dr. William Bronston (00:18:23):

So it's hard to communicate with your audience the magnitude of the problem and the relevance of the problem to your audience, because what's interesting here is that at the time when we were organizing in order to shut Willowbrook, we were very clear that number one, there were no community-based services in the state of New York. That is families either had to keep their kid at home or they had to put them, quote, away, unquote. And there were no small group homes, there was no habilitation services in the community. The schools excluded anybody with a label because society had not gotten to a place where people that were very different were afforded the rights of everybody else in society.

(00:19:20):

And the important thing here is that Willowbrook is just a large cancer that has metastasized in our society so that our entire society is riven with institutions for people as we grow older. As we grow older and become dependent in our advanced age, we are essentially channeled as a result of the financing of medical market services in our society to out of home segregated institutional services - nursing homes, assisted living and so on and so forth, hospice and the like, all of which are

terrifically profitable for the bureaucracy at the expense of the individual, and that terminus is what the book is all about.

(00:20:16):

What I'm concerned about is that people not see Willowbrook as a unique situation, because it wasn't. Even at its time, every state had numerous institutions, put aways, warehouses, concentration camps for people that were devalued and different in society, and that model, that paradigm, that economic reality applies today to our society in spades. The Medicaid system has plowed $6 trillion into our society in order to get rid of and monetize people that are no longer functional in the working class, in employment, in employability.

(00:21:01):

The situation with Lillian was... My reason for putting Lillian at the front of the book, first of all, was because she was just an extraordinary, poignant young woman. It's hard to describe. I went in there, I became a doctor to care, and I identified with the people that I was taking care of. They were me, they were my family. And what happened with this young woman, young African-American woman, preteen, was so horrible, and the institution's refusal to acknowledge or care for her and our attempt to get her out of the institution to Bellevue Hospital to be taken care of as a result of terrific head injuries that she experienced was so difficult a battle because the institution was just not interested in providing that care. That they just had no sense of the humanity or the integrity or the treasure that was in each of the young people that were in the facility. I just wanted to tell that story about her family and her, just as a case in point.

(00:22:24):

The book then goes into detailed stories of the kind of problems that everybody in that concentration camp experienced. It was an American concentration camp, monetized just like the German concentration camps were monetized. People made a lot of money by exterminating the unwanted populations in Europe at the time, the Jewish community, the gypsy community, the union community, the progressive community, the Slavic community. All of that was monetized. People had to handle food, laundry, transportation, cyanide in Germany and drugs in the United States, Thorazine, Haldol. And when you have 50 active people with nothing to do all day for every day of their life for years, people go mad. And in order to keep them somehow subdued, they have to be drowned in anti-psychotic medication to keep them mostly asleep most of the day, because there's only two workers on a ward for 50 people in a locked room. There's no way to take anybody outside because you either have to take all 50 outside because you can't have one worker take somebody out and leave one worker on the ward with remainder of the people.

(00:23:45):

So the situation was just staggering for me to grasp. What the hell was going on here? How such a model could possibly be valuable to the establishment. Not that it did not remove all of the problematic or challenging individuals that required a transformation of normal society to level the playing field, to make sure that everybody was properly empowered and enfranchised, but much less than that of just maintaining them at bare minimum life as long as possible in order to bring that Medicaid money in every day that they were in the hospital.

Maddie Crowley (00:24:27):

And what was really profound that it shouldn't be profound, but for folks who don't know about people with disabilities, people come to our podcast to learn about history or people's experiences, et cetera. I think what's so important to drive home as we talk about this, and it's

obviously a conversation throughout your book and throughout all of your work, is that institutional living, like in places like Willowbrook, was actually the thing that disabled and debilitated people, not the people themselves. They weren't bad, they weren't... They came in not experiencing what they would soon come to experience and how they would express themselves and things.

(00:25:17):

So I think we'll just continue that thread throughout this conversation, and what I'm hoping you'll speak to next is a bit about the politics. Unfortunately, politics and money and power are such a huge theme in this story and in institutional living today, and I was curious if you could, one, speak to your own experience and your role with the politics of the institution, but also help people understand, in as plain language and clear languages you can, how leadership used people with disabilities in order to secure more Medicaid funding by, for example, grading them with having a lower IQ than what they might have had, et cetera. Could you speak a little bit about that whole dynamic and really paint us a picture of what that looked like?

Dr. William Bronston (00:26:16):

So let me just sketch initially that my time at Willowbrook is really the context for this whole story, and from that context derives the insights into what message has to go to the general community in terms of system change. So first of all, when I first got there, I was assigned to this baby building, so-called baby building with 200 people. And after a couple, three months, the doctors in the building were so angry at my demands that we sit down and talk about cases and that we look at what was going on that they pressed on the superintendent of the institution to move me.

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And he moved me to a smaller building that was a grant funded building called the Hospital Improvement Program that had 134 preteens in it where I worked for a year. And at the point where I was able to completely clean that building up in terms of all of the tropical and incredible diseases that afflicted the children in that facility, I wanted to reorganize the kids in order to provide them with a home environment inside the facility that would ultimately lead to their matriculation back into society with the proper training.

(00:27:35):

And the nurses and the workers were absolutely organized to block that from happening, and I was moved again to then be responsible for two buildings, each of which had 200 adult women at the endpoint of the institution, and some days, I was responsible for five women's buildings on that side of the concentration camp of a facility. And then I was also responsible a couple of times a month for being on duty 24 hours to manage anything that happened in the institution that required medical attention.

(00:28:13):

And so here is this gigantic institution that I was driven through as a result of my efforts to make progressive medical proper change, developmental change, and I became deeply aware of what was going on. And as I demanded adequate clothing, adequate soap, adequate detergent for the floor, the elimination of straight-jacketing, the elimination of overwhelming drowning in antipsychotic medication, the efforts to try and provide proper diagnosis and management and follow up in order to eliminate the incredible amount of infectious diseases that were there just a result of hygiene, and also became hugely aware of the enormous violence, the barrenness and deprivation and dehumanization and depersonalization played in the lives of every single person in that place.

(00:29:13):

I would come to work every morning and I would literally have to touch everybody in my care to make sure that they were alive, because I would come to work frequently and find a dead person in my ward. Not in the little building that I was working in with my 134 kids, but in the larger buildings, especially in the women's buildings that I was assigned to at the end as a way of punishing me to try and get rid of me. And so the problem was just Herculean, and every day, I was working to serve the workers there because the workers were just one step above the residents in the institution in terms of oppression. They were unsafe, they were untrained. They were essentially involved in many instances...

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... involved in many instances with theft of all sorts because people would bring clothing for their children. The families that did visit, clothing would disappear, sheets, drugs, food, everything just drifted from the institution. We're talking about millions and millions of dollars of contracts that were essentially established by the state bureaucracy, not only at Willowbrook, but the other 29 institutions similar to Willowbrook that were operational in New York at the time. And they were building them at a very significant clip at the level of 30 or 40 or $50 million, $100 million per institution with a minimum of 200 people in them in all of the most barren places in New York as a way of the Republican Party and the governor there generating votes because of putting state jobs into remote places.

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So the politics of it were very obvious. In addition, the governor wanted ... this is Rockefeller wanted to build this gigantic office system in Albany in the state capitol, in white, marble and gold. And he essentially froze the budget and essentially removed one-third of the budget of the metal retardation service system, the institutional system in the state, which resulted in almost a third of all the workers essentially not being filled. And so whereas we were on the brink at the beginning with the budget cut and the budget freeze that lasted for close to six months, we were really in the most terrifying situation. And fortunately, I had, because of my relationship with Children's Hospital, I knew many of the top leaders in the world in child development because the clinic that I was working at was a world-class model clinic to deflect people from institutionalization, which was really the normal paradigm at that time in history before the disability community began to organize in order to fight for its human rights the way women did, the way the black community did and so forth prior to that.

Keith Casebonne (00:32:13):

And you touched on this a little bit, but I was hoping you could explain, dig into a little bit more, into the dynamics of the administrative staff, the ward staff, and the residents themselves, and how these roles of staff, you mentioned that they didn't have training, they didn't really know honestly much of what they were doing, how those pre-created roles. They became victims of the larger dynamic in similar ways to the residents.

Dr. William Bronston (00:32:38):

Exactly. Exactly right. The administration for the State Department of Mental Health, which had a commissioner in charge appointed by the governor, essentially operated out of Albany, and it had about 400 people and a budget of somewhere around $20 million in 19. $70, it would be roughly about $250 million in current dollars. And the institution that I worked at, all these institutions had an administration building where the superintendent and all of his supporters and clerics and so on

and so forth were housed. They never came to the clinical buildings where the residents were housed, never.

(00:33:32):

There was a hospital building where people that had acute problems could be sent if the hospital administration would allow that to happen. And then there were 60 buildings on the grounds of the institution, each with between 150 and 200 people were housed, 6,000 people altogether. The workers were essentially hired in large part from the poorer parts of New York and New Jersey. The majority were women of color and or men of color. They were state jobs. They had good benefits and they were better paying than most jobs in the community. And people clung to them very ferociously.

(00:34:24):

The institution was a closed system. So that essentially, the culture of everyday life resulted from the adjustment of the three shifts that came in during the day. There was a morning shift that came in at six o'clock in the morning and worked until three. There was a shift change at three. The workers at three o'clock worked until close to 11 o'clock at night. And then the night shift came in at 11 o'clock and worked until six in the morning. And each shift had a different culture. The upper part of the supervisorial and managerial staff of the institution left at four or five o'clock. And so the afternoon shift was without the same kind of supervision and rigor that the day shift was essentially suffering under.

(00:35:22):

And the night shift, of course, was a whole other world. And so the kinds of activities that went on in the day as opposed to the afternoon as opposed to the night were night and day. Literally, the difference of the personalities and the roles and the relationships that existed across the three shifts of the day impacted the people that were the residents on the ward because people were treated completely differently depending upon the personalities of the workers that were in those particular shifts.

Keith Casebonne (00:35:53):

Sure.

Dr. William Bronston (00:35:53):

And the kind of rigor, the kind of obligations and accountability that existed from shift to shift. What you're talking about is a closed system, absolutely closed system where the culture of survival was so complex and so challenging. And I was as a physician, responsible around the clock for the people in my building so that I had to come to know and understand the people on my three shifts by name. They became people that I counted on and trained, worked with. It was very complicated.

(00:36:34):

Now, at the same time, I was continuously demanding corrections to overt problems. For example, when I came there, nobody was using anesthetics to suture wounds that occurred.

Keith Casebonne (00:36:50):

Oh my God.

Dr. William Bronston (00:36:51):

And they were using virtually upholstery thread in order to close cuts and gashes. I demanded surgical material and anesthetics in order to take care of people because I was sewing up huge gashes at least twice a day, somewhere that I was working at as a result of people throwing chairs or being hit by keys or whatever it was. It was a horrible situation. And so I was going to the administration in order to deal with everything from the sickening food that was causing diarrhea, the mash and mush, and the way that people were essentially forced fed because there was only so much time to handle food feeding situations with the ward because many people were not able to feed themselves, there were no utensils, there were no dishes, there was nothing human, nothing normal in that facility.

(00:37:46):

And again, I want to say that I believe that the nursing home industry today is in its own way as violent and guilty and barren, and dehumanizing as what I was dealing with. It's just that it's advanced a little bit. It has some more shine at the front end. It has more individualization at the front end. It has more permissiveness because people ... Essentially families put their elders or their dependent members into these out-of-home placements because Medicaid will not pay people in order to take care of their dependent members. Medicaid is set up by law to only fund institutions, facilities. The money goes from the Feds to the institution, not through the family, which is part of the whole crime that exists.

(00:38:41):

So as I began organizing at Willowbrook, I began to understand why there was inadequate clothing, why there was inadequate sheets, why there was inadequate soap, why there was inadequate medications, why there was no proper medical consultations, why nobody left the institution except fee first, because the longer they were kept there, and regardless of the most wretched circumstances, money was flowing into the state of New York from the feds in order to fund and maintain that institution in tens and hundreds of millions of dollars.

(00:39:17):

And that the state was generating more and more institutions as opposed to community-based services until after we filed the federal class action lawsuit for crimes against Humanity against the governor and the state of New York in order to close that monstrosity and others down in the state.

Maddie Crowley (00:39:36):

So that is such a good segue to ... I'm really hoping that we can really iron out the connection between Medicaid and more Medicaid money going to the state and how even with more money going to the state that these folks still didn't get any care. Could you just try to clearly paint the picture for us of, so for example, doctors were encouraged to give them lower IQ ratings to get more money to that institution, but then when that money was sent with the intention of saying, Hey, this individual might need more care, because at that time, lower IQ was thus connected to maybe needing more personal assistance or sanitary assistance, that was the connection they were making with getting more money to that individual, but can you explain how that never happened? Did that money go to building more institutions? Did that money go to admin? Where did that money go?

Dr. William Bronston (00:40:48):

Yeah, so let's be very clear. The purpose of the institution was to essentially warehouse unwanted human beings that had to be in terms of our economic system modifying, monetized

commodifying. And the way in which the federal government worked in terms of financing institutions was through the system of Medicaid funding, which was established in 1965 when Medicare was established.

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Medicaid essentially provided 50/50 funding to states, 50% from the Fed, 50% from the state in order to cover the facility costs of the people eligible for Medicaid, who had to have less than roughly $2,000 of total assets in their lives and essentially require out-of-home housing by law. So what happened was that every day, depending upon the census of the institution, the feds provided dollars to the state, the money that was provided to the state, this 50/50 money essentially was tiered depending upon the theoretical degree of service and care required by the individual, which hinged upon the gravity of their special needs, their disability.

(00:42:25):

We were instructed by the institution of Willowbrook, which was, of course, instructed by the state Albany Commissioner's Office to upcode maximally everybody that we looked at that we have to look at every three months or every six months in terms of providing a review for the federal government. So we were told to make sure that we diagnosed the people in our buildings with the maximum degree of disability to get the maximum reimbursement from the state. And we had to evaluate at one point everybody in our charge, one at a time in order to record and document and recommend the maximum funding, which I refused to do outright, openly, publicly in the doctor's meeting when we were instructed to defraud the federal government with our findings.

(00:43:27):

That is to say by saying that a person needed to be in institutional placement and that they had maximum needs was essentially to consign people to a downhill extermination at some point because there was no program anywhere in the institution to habilitate or rehabilitate the people in the institution. They were there at minimum cost to the state and this money that was coming in ... So, Medicaid was roughly spending roughly about three to $500 per day per kid, per resident, times 6,000. And that money went into the state treasury, the state of New York Treasury.

(00:44:25):

The state had a very complex and major organizational apparatus in order to use federal tax money and state tax money to expand public services like schools, public housing, mental health clinics, and institutions for people with mental retardation in the state. And that entity essentially would establish loan blocks of money that would essentially finance construction, and that those loans were offered to the large financial institutions in the state of New York in order to get the interest money from the loan to the state of California for the construction.

(00:45:24):

The bids essentially were aimed at the lowest possible cost for the projects that were envisioned by the housing and finance entity at the state level. Most of those banks belong to the Rockefeller family, most of them. And so what was happening was that as Nelson, the governor was essentially plotting with his political administration to expand public services, we're talking about building systems capital expansion. His brother David was the head of the major banks in New York State, national global banks, and was able because of size, to offer the lowest interest rate to his brother to loan him money.

(00:46:23):

Then when that happened, then there were contracts that were led in order to support the political party in power to establish contracts with lawyers, with accountants, with construction people, with a variety of institutional services, transportation, so on and so forth. So you were talking about tens and hundreds of millions of dollars. In fact, the governor when he came to power, essentially established with the state legislature, the possibility of borrowing $ 1 billion in order to expand the public services in the state, which was not meant to serve people necessarily, but as a financial strategy in order to increase the wealth of the people engaged in those transactions. Whether or not what happened was properly staffed, properly organized, aimed at transforming and upgrading society and the quality of life for people was totally beside the point.

(00:47:38):

And so when we talked about the need to deinstitutionalize the state of New York, we were essentially challenging the whole economic foundation of the largest banks in the state and the political party in power in the state in terms of the enormous amounts of money that were flowing into its coffers and the enormous amount of influence. It was able to exercise in the expansion of the institutional system with no consideration for non-capital expense-based services that essentially would've changed the cost of care drastically and massively improved the way in which people were essentially empowered, trained, educated, and supported to participate back in society and being contributing members in the economy as well as in the society.

(00:48:35):

So at the time, the society was essentially stripped of differentness. All culture of the society was made to be as accommodating to people who could walk, talk, think as possible. And if you had some variation in your ability to walk, talk or think, then you essentially had to be removed from the society because there was no support systems. Meaningfully public education system was not taking anybody that was deaf or blind or had mobility issues or had thinking or differences and so on and so forth. And so this whole tremendous stigma, the stereotype that was against anybody different impacted the entire society. And the irony, the incredible insane irony was that as people aged, they began to develop these differences just by virtue of aging.

(00:49:34):

And all of that was driven by this gigantic treasure of federal tax money, Medicaid money in order to remove people from burdening, challenging the normal cultural realities, staircases, door width, ramps, all of that stuff that essentially we now take for granted as a result of the enormous impact that the organized disabled community has influenced the general society through lawsuits and through their mobilization, through the Americans with Disabilities Act, through the reformation of the Federal Rehabilitation Act, through the transformation of the education system because as a result of our lawsuits in 38 states, class action lawsuits against states for crimes against humanity, for institutionalization, the education system essentially established the most radical model for people in the small group called developmentally disabled.

(00:50:41):

That is people with mental retardation or cerebral palsy or autism or epilepsy, or some learning disabilities, not everybody with a disability, but a small group essentially driven by the Association for Retarded Citizens who are always at the bottom of the service barrel as it resulted in forcing the school system by law to adopt services to meet the individual needs of the student rather than the student being forced to comply with the limitations of the school system.

(00:51:16):

That was a revolutionary transformation of priority. We did the same thing in the Rehab Act where we turned the Rehab Act upside down. And this is a result, Madeline, as a result of all of these suits that were being filed against institutions, because the mobilization of testimony and plaintiff family leadership and professional, progressive professional leadership essentially altered the whole thinking about dealing with differentness in America.

Maddie Crowley (00:51:48):

Yeah, and I wanted to pick up on something specific that you said, especially when we're talking about this in context in our history, like institutions, like you said, were like Willowbrook, were just freely able to happen because there weren't any laws like the ADA or the Rehab Act. At that time, those weren't passed yet.

Dr. William Bronston (00:52:17):

That's right.

Maddie Crowley (00:52:17):

And I think what's really important to hone in on here, and I remember an example from your book that you shared was for maybe a single mom who had a child with a disability who was not allowed to go to school. They lived in New York, so there were no home and community-based services. If that mom had to work, she had no option but to have their child placed into an institutional setting.

Dr. William Bronston (00:52:46):

That's right.

Maddie Crowley (00:52:46):

So I think that's really important to take home too, is that it's not that people were, I don't know, they were ashamed to put their children in these places, but it's also, it was a matter of necessity for people to maintain their lives, maintain housing, to whatever the case is, to be able to work, to be able to have income. And I'm curious if you can speak a little bit more to that emotional violence done to families by the institution to bring in more young, disabled folks to live there because when we pan out and think about how many people were impacted by this, yes, the residents were the most directly impacted, but the families, the ward staff and folks, they were essentially manipulated to feed into this whole system without having the ability and autonomy until you talk about the parents and their advocacy and their organizing to help create some visibility on this, whether that's the expose, whether that's the news articles, whether that's the lawsuits, et cetera. But everyone kind of was upon in maintaining this system. So could you speak a little bit more to that impact and the impact of the emotional violence done to families and where that eventually took them once you started connecting with them and saying, Hey, this is actually what's happening despite the leadership at Willowbrook denying your ability to meet with families either on the ground in your own personal time, et cetera, and how that helped them move towards demanding accountability for their family members, for their kids living in Willowbrook?

Dr. William Bronston (00:54:41):

So my experience at Children's Hospital derived directly from the mobilization of families bringing their kid with suspected slow development to the clinic in order to be essentially worked up. And so

my paradigm, my understanding was always that the parents of a young child were the critical force for the transformation of expectations and services and quality of life of that particular child.

(00:55:12):

So at Willowbrook, one of the things that happened was that when people were recommended to be institutionalized, they were told by the professionals, stay away for one, two, three, or four months to allow your kid to "accommodate" to this new situation because if you come and visit too early, which just creates problems for us here at the institution in terms of the kid being upset. So my first effort was as quickly as possible to-

Maddie Crowley (00:55:43):

Also, we're talking about kids, we're talking about five-year-olds who are taken away from their families.

Dr. William Bronston (00:55:48):

That's right.

Maddie Crowley (00:55:49):

And you're saying don't visit them for months. I'm sorry, I just needed to emphasize that. That's so sad.

Dr. William Bronston (00:55:54):

Exactly. So what happened was ... And the whole facility was essentially a fortress. You had to go through two gigantic locked iron doors to get into any of these buildings, and God knows what was behind these doors in terms of image. And so I began to make sure that as families came to visit, number one, I was there to meet them and sit down in my office and talk to them about their kid and why their kid was being turned into a ground meat. Every time they would come, the child would be more and more badly injured and scarred because of the violence in the institution, in the facility.

(00:56:36):

And I've got to know these families profoundly. And we began to work on them taking their kids out and preparing the workers to not reject the family and to show them where the young people slept, where they ate, where they spent their day, so that families could see the reality. Families were never shown the concrete reality of the experience of their members that were institutionalized. And the families were very confounded at the beginning.

(00:57:14):

First of all, guilt and shame, and ignorance are just the three horsemen that afflicted these families. And so I had to really spend a lot of time sitting, with talking, with crying with these families about their mortification, their sadness, their shame, and to somehow stop them feeling badly about the fact that the kid was in the institution or the person was in the institution because they had no choice, and that to be explained to them.

(00:57:50):

So let me tell you. First, part of my hope was to help organize the workers through their unions in order to demand better working conditions. But that is explained in my book in detail of why that didn't work. Although I was an experienced labor organizer, despite the fact that I'm a physician,

that didn't work. And so I had to turn to the next more reliable community, and that was the families. And so I had another physician colleague of mine, Mike Wilkins, who I brought in to work with me to work on the other side of the facilities on the men and male side, and I was on the female side. And we essentially did the same thing. We brought families in. We began to have meetings with the families about how things could be improved, what work could be done, what the problems were and the needs were in the institution. And as the families began to shed their sense of themselves being the problem as opposed to being the solution, things began to change.

(00:58:56):

And they began to go to the administration demanding, meaningful, systemic changes in the system, not just a little favor here and there for the small group of families that essentially sucked up to the administration to maintain the status quo, which had been going on for two or three decades, but to really have some meaningful accountability of the violence that was happening in there, the lack of adequate clothing, the lack of security of the overuse of tranquilizing medications, straitjackets. One family member said to me, "Why are you signing these?" I have to sign a straight jacket approval every day for a kid to be in a straitjacket by law. But the fact was that we have lots of kids in straitjackets day in and day out, month in and month out, year in and year out. And I just had to sign these things every day. I had to sign drug renewal approvals for them. And the family said to me, " Why are you doing this?" And I thought, "Jesus Christ, why am I doing this?"

(01:00:03):

Why are you doing this? And I thought, Jesus Christ, why am I doing this? Why am I doing this? But in order to stop doing it, I had to deal with the terror of my workers, who in many instances were really afraid of the people that they were taking care of, because the conditions that they had to take care of people resulted in a lot of violence coming from the residents that were just reacting against the drugs, against the boredom, against the emptiness of life year in and year out. So it was a major effort to begin to build, first of all, a trusted relationship with the families, and secondly, to bridge the relationship between the families and the workers who were essentially kept divided by the administration. As long as the workers didn't trust the families, were afraid of the families, would wrap them out in some way or another and cause them to be fired, they were terrified themselves.

(01:01:02):

So everybody was kept on edge and kept divided. Mike and I worked in our respective buildings. Then afterwards, we'd have dinner together. We had a family group, a large house in Staten Island together. We began to build these bridges. Little by little, the situation in the institution began to change. As the families began to organize and demonstrate for major change, for adequate staffing, adequate training, adequate clothing, adequate food, adequate medical attention, the administration became more and more dysfunctional. The superintendent who was this big pompous guy essentially exploded at the families and fired Michael and his two social workers. They couldn't fire me because I had a lawyer and I had filed grievances against them to block them from firing me while I was trying to fix the situation. As the families grew stronger and stronger, then they began to seriously sit down with legal aid and ACLU lawyers in the region in order to file suit against the State of New York for human abuse, crimes against humanity administering these institutions.

(01:02:24):

So they became the critical spear for change, and that change was deeply democratic. The mobilization of scores and scores of families resulted in this campaign to essentially ... The other

part that we were doing was I was inviting the top leadership in the world in mental retardation to come to visit Willowbrook. We would tour them through the institution. Then we would essentially provide major opportunities in the community for them to give talks with hundreds of families there to describe what community services were like as opposed to institution services, which only strengthened the families. Then the newspaper people in the local area got into the act. Geraldo Rivera was called in when Mike was fired in order to photograph without any censorship, the horrific circumstances, the squalor, the violence, the shrieking sounds, the smells. When that showed up on ABC television, it catapulted him into stardom. That story was just amazing and it was really one of the major triggers that transformed the movement towards the federal class action lawsuit that the families engineered against the State of New York to shut the place down, which took 25 years.

Keith Casebonne (01:03:45):

And I'd love to talk a little more about how that interaction of the media coverage, Jane Kurtin, the articles that she wrote, of course you already mentioned Geraldo Rivera, all of these things along with the families finally starting to see the light coming together, being informed a little bit more. There was, of course, there's also some federal government input, and all these factors together still couldn't close it, right? It still took forever to close Willowbrook, so can you talk a little bit about those different forces, and how they started working together, and still yet, it was such a challenge to get this prison ... Honestly, when you mentioned the large metal doors, I'm just thinking, is this a hospital or a prison? But if you could talk more on that-

Dr. William Bronston (01:04:23):

It's not a hospital nor a prison. It's a concentration camp. It's like a prison, but not. It's a unique critter. So that question is very interesting because we really are dealing with an unbelievable amount of money and tens of thousands of people whose livelihood depends upon the status quo. For example, my solution to this institutional culture that we have is to establish a comprehensive, universal, rightful, single-payer, single trust fund for all health services in America. That would fundamentally end the institutional system and deal with myriad crimes that exist in our society. The objective here was to somehow introduce the need to shift the economy of the banks, of the government away from these gigantic capital expenditure based models to service models in the community that would transform society, transform people's relationship to one another.

(01:05:53):

The challenge to alter people's consciousness, their understanding of the status quo, their understanding of what's possible, and to somehow deal with a different kind of an open society is not an easy thing to accomplish. There are major struts in the ground that hold these large employment entities, these large union entities, these large economic entities in place, and they serve the oligarchy. They serve the richest elements of society. They serve the ownership class in America in a way that allows them to monetize people that are not in the workforce, elders, people with disabilities, people that are very different, people that are not particularly competent, whatever. So we didn't realize we were really squaring off against capitalism.

(01:06:54):

We were squaring off against the whole economic system that essentially grounded everybody with an ideology and a mass media propaganda system that kept the status quo in place on behalf of the richest elements in society. That's why the story about Willowbrook is so profound and so generic. It tells the story of one gigantic cancer that has now become a gigantic metastasis that has

institutionalized our society. Unwanted people that are not able to be exploited in their jobs through minimum wage and whatever are essentially monetized. The oligarchy is monetized through the financing of federal tax money, what I call the public ransom. All of these people in these facilities that are essentially different, that are essentially excluded from life because of various dependencies are the public hostages.

(01:08:05):

The problem is that the ransom does not emancipate the hostages. The ransom is paid in the hundreds of millions and billions of dollars every year in order to keep people out of the workforce that are not major contributors to the workforce through the normal efforts of wage slavery in the society. So the story of Willowbrook is a story that leads to the need for a systemic solution in our economy, and that is universal, single-payer, rightful healthcare for every single man, woman, and child in society. We're talking about something in the vicinity of $4 trillion, which is currently spent in the medical market system that essentially is connected to the removal of thousands of people from society and thousands of people from earning an income. For example, many of these parents who now may keep their dependent members home can't work at the same time they keep their member home, so that you have in the United States, 41 million people who are doing unpaid work to care for members of their family that need services short of being put into an institution

Maddie Crowley (01:09:30):

Yeah, and to bring it to Florida, and I'm sure you're aware of this issue across the country, we have waivers in Florida that are 22,000 people long, people that have already been approved of getting home and community-based services, supports, staff, et cetera, that quite literally just don't get it. It's the same exact conversation that you're having where it's families that have to take off work to support a loved one or not work to support a loved one.

(01:10:05):

I think especially now, and I'm going to continue how we're pivoting towards present day, especially now as the federal minimum wage is not being raised from when it was last wage in 2001, sorry, 2009, and how the wealth gap in the country has just continued to grow and grow to the point that it's the largest it's ever been in our history. I think you mentioned Willowbrook being this change-making moment, but also just normal moment in history. I really feel like there is, as you're talking about single-payer healthcare and discussing the importance of that and the autonomy and power that will give back to people, I think as people are really starting to feel the difference and feel how they're personally impacted by the inequality of capitalism and the wealth and income gap, I think this conversation is really starting to be more salient for a lot of people.

Dr. William Bronston (01:11:19):

The disability community in America needs to somehow understand that they are the vanguard for health and social justice in America across the board, not just for their individual dependent family members, but for all of us. Because what we need, what the disability community needs is needed by 100% of the population, security, choices, liberty, support systems, resources, care, all of that, housing, all that, education, transportation, all of that, we all need. The disability community is already organized in these amazing civic structures, the Association for Chartered Citizens, the United Cerebral Palsy, Epilepsy Association, Autism Society, and so forth. The mental ill community and especially the primary recipients of services are organized, people first in the mental retardation community and the mental illness community. So this is a social movement, similar to the senior community that has a big stake in health and social justice, and they have to

understand that the solution to their problem has to be couched in the solution for everybody's needs, not just their own.

(01:12:48):

They cannot see themselves as a categorical advocacy body demanding services for this or that diagnostic grouping, whether it's Down syndrome or general mental retardation or spina bifida or muscular dystrophy or whatever. We have to have a rightful campaign that generates law in America to establish universal rightful healthcare, which affects 100% of the American population on an individualized basis with a single tier of Cadillac quality care for which we have so much extra money that it's shameful that this hasn't happened. But the money has been essentially siphoned off into the oligarchy. What we have here is a medical market system that's a wealth transfer system that essentially dehumanizes, insults, violates everybody in America. Everybody's walking around with fear in their heart, whether they're conscious or not conscious of it, of something awful happening to them that they can't cope with, that they can't afford. We have to end the linkage between wealth and wellness. Wellness and wellbeing and good services have to be a right, a public utility, a good in society and not a commodity.

(01:14:12):

We cannot sell medical care and be essentially a civilized and humane and ethical society. The story of Willowbrook that's built into Public Hostage, Public Ransom: Ending Institutional America, my book, essentially deals with that in as much detail as I'm capable of saying. Everything I understand, everything I've learned in my life is all poured into that book. And there's now a website that is called OurHealth.pub, dot P-U-B, dot public. That website essentially is a model derived from the need for universal single-payer healthcare in the book that has to be essentially discussed and embraced by the advocacy community in America that is driving towards a universal healthcare system, a single-payer healthcare system in America with one tier of care, ending the middleman entirely, outlawing the private insurance industry, and essentially bringing the pharmacy cartels and the hospital cartels and the insurance cartels to their knees in order to establish rightful, empowering, and franchising wellness in society.

Keith Casebonne (01:15:30):

Wow. So tell us a little bit more about the work and advocacy that you do now regarding healthcare. You're already touching on the website and stuff that you're involved with. Just to close out, if you want to tell us a little bit more about what you're currently doing, a little bit more about your book, and what people can do to keep things going in that direction that you outline.

Dr. William Bronston (01:15:49):

I belong to an organization called the Physicians for a National Health Program, which has 30,000 of us physicians and other health professionals throughout the country that are driving, first of all, to establish a universal single-payer, rightful healthcare system in America. That's going to require law. The same incredible challenge to close the Willowbrooks and the institutions in our society is going to be dwarfed by what it's going to take to transform our medical market system into a true rightful healthcare public good. We all know that the whole injustice and the insult of having to pay for something that you need that's not your fault because of your own health situation has got to be changed. So that agenda is, short of climate and short of ending wars in the world, the single most important social policy issue that affects 100% of our population. People have to own and drive that campaign through their churches, through their community organizations, through their advocacy work, through their civic engagement.

(01:17:07):

They have to demand universal single-payer healthcare with no incrementalism. It's a one step jump from what we have now in policy of a medical market system to a public good healthcare as a right in America with a single tier of care across all needs in society. The work that I'm doing now is to build in the State of California a campaign dialogue around my website, around OurHealth.pub. The California Nurses Association has been for decades the single most important organized body of union workers that has demanded and generated model legislation in California and at the national level through Pramila Jayapal's single-payer bill out of Washington. She's a Congresswoman, and the National Nurses Union, which is the national manifestation of the California Nurses Association, are driving this effort to establish single-payer healthcare. In California, the bill is going to be called CalCare, and I'm in the process of working with the nurses now in order to expand their idea, their model of single-payer healthcare to include issues of eliminating all medical debt.

(01:18:32):

We need to buy out all medical debt upfront in order to establish a healthcare system. Number two, we need to organize, and this is stuff that I'm doing every day, literally 24/7. We need to establish the public health system at the top of the healthcare delivery system in America. What we have now is a medical market system at the top of that system that's all driven by money, purely driven by money and power and influence. That has to be completely changed to establish public health prevention, early intervention, and the coordination of housing, education, jobs, transportation, food. The whole nine yards have to be essentially coordinated, because 90% of wellbeing comes from those social determinants, not from medical care. Medical care only accounts for 10% of our wellness. We need to have wellness, wellbeing, civic engagement, creativity, inspiration as the goals of our healthcare system, not the end of illness.

(01:19:45):

The end of illness is just the beginning of the transformation towards wellness. So the campaign for single-payer that's going on at the federal level and at the state level has to be driven. CalCare, the nurses model has to be understood. It's going to be essentially framed in January or February of 2024, the most current bill that they're going to submit. And I'm hoping to be able to influence them through meetings with the assemblyman that is currently supporting their bill. His name is Ash Kalra. He's going to be the author of the CalCare bill in California, but I believe that people are going to have a direct vote through a proposition, because I don't think that the California legislature is not sufficiently prostituted by the big lobbyists to vote for something that would essentially end the sweet money deals that many of them are essentially enjoying behind the scenes, regardless of what they say upfront.

(01:20:52):

We're going to have to have a public vote, which is going to mean raising 50 or $60 million with a media campaign to offset the distraction and the disinformation and the terrifying efforts, the scare tactics that the cartels are going ... the insurance, hospital, and pharmaceutical cartels are going to launch in order to block the people from what's in their own interest. The Willowbrook story is the open door to the reality of horror and abuse and violence wrecked upon us by this current economy. The website is the model, the most advanced and most imaginative model of a universal healthcare system that 40 of us were able to craft over a period of a year working together around the country. And the legislation that's being driven by the California Nurses Association, the CNA, that's going to show up in the California legislature in January is going to be the first major effort in this coming year in order to make change.

(01:22:01):

We're going to have to understand that all of these drug ads that are on MSNBC and every place, all the insurance ads, the whole privatization of Medicare and Medicaid through their Medicare disadvantage kind of operation that they're selling, and the whole effort to try and move all the seniors without them knowing it into a privatized system where they would have limited networks of who they can take care of, who can take care of them, and so forth, has to be exposed and blocked. The task is absolutely mind-boggling. We have something impossible to do, but without that inspiration of having to face the impossible, life would be really boring. We're [inaudible 01:22:48] about because the country cannot afford the continued unaccountable inflation imposed by the cartels to increase the cost of being well in America.

(01:23:02):

We have to end this market economy around medical services and establish a true healthcare system. So that's what I'm working on day in and day out, and I'm hoping that the book will make a difference. I'm hoping that the website will trigger conversation all around the country. The organization that I belong to and its partnership with the California Nurses Association is a key iconic ... We're the health professionals, progressive health professionals, committed to essentially challenging the market economy in health and medical services in order to change the society. We are coming out of a terrible period as a result of the last administration prior to Biden in terms of looking at our democracy.

(01:23:52):

So the election in 2024, the outcome of the multiple felony charges against the past president, the way in which we're going to deal with the incredible serious existential crisis from climate change, the need to nurture, expand, enrich, and humanize our democracy, the struggle to essentially address the discrepancies that are a part of the racism and essentially anti- different society that we live in are part of the context of everyday life for all of us. It's an overwhelmingly and intimidating challenge, but somebody's got to do it, and everybody's got to at some point. That's my life. That's my life. My life is health and social justice, because wellness, being community, caring is fundamental to being a human being in the world today, always.

Maddie Crowley (01:25:02):

And I think that is a beautiful way to close out this episode, as that just invokes such a strong call to action to learn more about the history that we've laid out, is just really, truly just an overview of everything that has happened through Willowbrook, through other institutions, up after and in the deinstitutionalization movement, and even to where we are today with the work that you're doing. So I am so incredibly honored and thrilled that you were able to join us today to talk through all of this and really paint such a strong picture for the listeners and readers of the transcript who will be able to be even more informed about how all of these things connect and what the most humane and respectable and just needed changes are to come next.

(01:26:08):

I really appreciate you giving us your time to lay that out and just thank you for all the work that you've done. I think just framing it as closing Willowbrook seemed impossible, and I think a lot of people think these things are impossible or unattainable, but you have stories and proof that it is possible. So I really appreciate your time and your energy today. And Keith, do you want to say anything else?

Keith Casebonne (01:26:35):

Oh, same, just honored that you're here and had the same feelings that Maddie has, that it's a nice positive direction to end what's a really sad and negative story. But how that can affect positive social change is really I think one of the important takeaways from the whole discussion.

Dr. William Bronston (01:26:52):

I'm terribly grateful for your time and your openness. People have to understand that they have to belong to something more than just themselves. They're not just fighting this thing by themselves. They have to understand that they have to be part of some kind of a group that's concerned with being social and health justice. So whatever it is that you have to belong to, whatever it is, whether it's the transgender campaign or the literature issue or dealing with the fascism that we're confronted with in our body politic today, they have to do that. Don't be alone and don't feel that you don't matter. Every one of us matters. I knew that I had to close down Willowbrook by myself, but I had to organize scores and hundreds and thousands of people over a period of two or three years in order to make it happen. But I knew that I could make it happen, and it had to happen, because that atrocity had to be ended. And the atrocity that we live in every day has to be ended. You all that are listening are the source of the change in America.

Keith Casebonne (01:28:03):

Very good.

Dr. William Bronston (01:28:04):

Thank you very much, my friends. I'm really grateful.

Keith Casebonne (01:28:06):

Thank you so much.

Maddie Crowley (01:28:06):

Thank you.

Keith Casebonne (01:28:07):

Appreciate your time. Hey Marlene, thank you so much for being on our show today. If you could introduce yourself, tell us a little bit about who you are and what you do, we'd love to hear it.

Marlene Sallo (01:28:18):

Sure. Thank you so much for having me, and as you indicated, my name is Marlene Sallo, and I'm the executive director for the National Disability Rights Network. I've been here for almost a year, so coming up on my one-year anniversary. I am the first woman, the first Latina, let alone the first person of color, and first person with a disability to lead this agency, so lots of firsts, which means a lot to me. I am a civil rights attorney, and as I tell anyone who will listen is I'm a civil rights attorney, but I'm also disability rights, right? Because civil rights is disability rights, and it's human rights. So it's one big umbrella.

(01:28:58):

I consider myself a zealous advocate for children and youth with disabilities, especially those involved in the juvenile legal system, as well as the child welfare system. And I'm very happy to be here today, because I started out my work in disability rights law at Disability Rights Florida years ago. So it feels like coming home. By way of background, I've also served as the executive director of the P&A, the Protection and Advocacy Agency in Massachusetts, prior to being honored to serve as the ED here. Every day that I come to work, I'm thankful for this job and for the ability to truly lift up the voices of great staff across the network and across all of our protection and advocacy agencies as we work to secure and support the rights of all people with disabilities.

Keith Casebonne (01:29:48):

Well, it's great to have you back home where it all began.

Marlene Sallo (01:29:51):

Where it all began.

Keith Casebonne (01:29:53):

That's right, and congratulations on all those firsts, because those are all very important, and it's really great to see that as part of now just the history of the P&A network itself.

Marlene Sallo (01:30:03):

Yeah.

Keith Casebonne (01:30:03):

... As part of now just the history of the P&A network itself.

Maddie Crowley (01:30:03):

Yeah. So thank you again for that introduction to yourself. You're an incredible advocate for folks with disabilities. And as a person with a disability myself and as you named yourself, I think having folks with the identities leading the organizations that those identities are due to serve, I think is so crucial. And I'm sure you're going to talk a bit more about that. But before we get into that, we just heard Dr. Bronston's interview about Willowbrook. So let's pick up where he left off talking about the history of the P&A network. How did it start? What was the significance of Willowbrook in that history? What's Olmstead kind of piecing together these different components that have thus created the wide network that is the National Disability Rights Network or the Protection and Advocacy Network?

Marlene Sallo (01:31:00):

Yes, absolutely. So for those that are unaware, the first protection and advocacy program was called the Protection and Advocacy for Individuals with Developmental Disabilities, right? And that was created in 1975, and it was created after a series of television reports about Willowbrook, especially the expose that was done by Geraldo Rivera, which truly exposed the deplorable conditions at Willowbrook. Now, his expose took place in 1972, but I just said it took three years for the PADD to go into play, but it didn't come to light what was going on in Willowbrook just in 1972, because back in 1965, Robert F. Kennedy was aware of what was going on in Willowbrook. And he was quoted as saying that it was a snake pit, that when he had gone in there, he had observed that

children were actually living in filth while living there. And I hate to use this word, but this is literally what was happening, is that folks were being warehoused, individuals with disabilities, and back then they used the MR terminology, but it's what we would say, intellectual or developmental disabilities were being warehoused in this facility.

(01:32:17):

There was no stimulation of any point, no education, nothing. They were just existing in that facility. But Willowbrook wasn't the first organization, right? Or lack there ... I wouldn't even call it an organization, institution that was doing that. History shows that since the 1800s, many individuals with disabilities were confined in large segregated institutions that often provided inadequate care, limited or no autonomy, and isolated them from society and their families. And so we also know that these concerns were not just for individuals with intellectual and developmental disabilities because there were also concerns about abuse and neglect of individuals and mental health institutions. And that ultimately led to the enactment of the protection and advocacy for individuals with mental illness in 1986. But we really need to put this a bit more context around it. Right? While the PADD act was passed in 1975 as a result of the expose, it wasn't until 1978 that protection and advocacy agencies began operations at the state level with state designations.

(01:33:35):

Now, fast-forward to today, we have 57 protection and advocacy agencies, one in every state in US territory. And we also have a Native American Protection and Advocacy Agency, which is currently in the Four Corners Region of the Southwest. So our network, as it stands, is the largest provider of legally based advocacy services for individuals with disabilities. But we wouldn't be able to truly conduct the work that we do without the multiple civil rights laws that exist, like the Rehabilitation Act of 1973, which is section 504. And that act provides equal opportunity for employment with the federal government and in federally funded programs, and also prohibits discrimination on the basis of disability. We have the individual with Disabilities Education Act, which allows students who have a disability to receive services in schools, and then we have the 1990 Americans with Disabilities Act. But I think what folks don't realize is that it was the 1999 Supreme Court ruling Olmsted versus Lois Curtis and Elaine Wilson that directly addressed the institutionalization of people with disabilities.

(01:34:54):

And this ruling stated super loud and super clear that it is a violation of the civil rights of Americans with disabilities to require a person to be institutionalized and to receive necessary disability supports and services because we know as a result of Olmstead, that these services are more appropriately provided in the community. They are being provided in the community, and individuals with disabilities are thriving outside of institutions. And so you put all of the enactment statutes for our network along with the civil rights laws that are on the books along with Supreme Court rulings, as important as Olmstead and others, and all of that put together really provides us, in the network, with the opportunity to be zealous advocates for individuals with disabilities so that they can choose where to live and where to work, and just to be free to make their own decisions.

Keith Casebonne (01:36:00):

I hear so much about the dates that you're saying, and I think, gosh, we're talking about 1972, even before that, you mentioned in the '60s, Senator Kennedy, his experience, and then we're talking 1999 Olmstead, and of course, it's 2023, and we all still have jobs because this is still going on. So it's such a long journey, and absolutely things have happened. There've been accomplishments for sure, but there's still so much going on. And so tell us a little bit about the significance of

Willowbrook and Olmstead and the Deinstitutionalization Movement, that significance that we still have today, that impacts our work today.

Marlene Sallo (01:36:36):

Right, impacts our work on a daily, every minute of every day, because that is the center of the work that we do, is to ensure that individuals with disabilities have that right to choose. And so I think when we think about the initial focus of the PADD act, the Developmental Disabilities Act, and then the subsequent P&A statutes that were put in place, and there's a total of nine, the gist of that, the core reason for that was to safeguard the wellbeing of individuals living in institutions. And that, to this day, as I said, remains a major focus of all the work that we do. We continue to monitor, to investigate and to remedy or attempt to remedy adverse conditions in large and small, public and private facilities that care for people with disabilities. But as P&As, we also assist persons with disabilities to find living arrangements that are the least restrictive as possible.

(01:37:34):

We have been at the forefront of the Deinstitutionalization Movement, and over the years, the focus of our work was broadened to one that secures the rights of persons with all types of disabilities, wherever they live, wherever they reside. And so as a result, the statutes have been expanded to give the P&As additional authority so that the P&As can now devote considerable resources to ensure full access to inclusive educational programs, financial entitlements, healthcare, accessible housing, accessible transportation, and productive non-segregated employment opportunities, while we continue to seek prevention of abuse and neglect of any person with a disability, where they reside, where they work, et cetera.

Maddie Crowley (01:38:24):

Yeah. And tying all of the years and dates that you noted, it's really crucial to connect that in that history to where we are now. Because like you mentioned, and Keith briefly mentioned, this is still going on. People are still living in institutions because home and community-based services are not fully actualized. Mental health responses isn't equitable to a variety of different communities. And I think it's important really to note how ... that's a very brief way to note how the disability community is still impacted by this history. It's almost ironic because we "deinstitutionalize," we wanted to work to deinstitutionalize places like Willowbrook. But now as we get further, especially our IDD populations grow older, they're now finding their way back into these residential living situations rather than potentially living in the community. So could you speak a little bit more to how the community is still directly impacted by this history and kind of what ways the network is working to continue to address this?

Marlene Sallo (01:39:45):

Yeah. So the first thing that comes to mind in the work that I've done as a court appointed attorney on behalf of youth with a mental health diagnoses is how we continue to place youth with that diagnoses in residential facilities. And how many of those residential facilities have done more harm than good. And so why is that necessary? Well, the system that we are dealing with is short-changing our youth. The systems and how they work together or not are not providing the comprehensive services that are needed. And then for our youth upon reentry into their community, whether they are coming out of a residential facility or they're reentering after being in a juvenile detention facility, the wraparound services, the connective fibers that should be in the community from a service delivery model are not there. We're seeing in New York City and in

California state how we're trying to criminalize houseless individuals with a mental health diagnosis.

(01:40:57):

And so time and time again, we are seeing the systems, the over-criminalization of individuals with disabilities taking place as a result of systems not providing the services that are warranted, that are needed, and that individuals deserve when we're all ... There are certain communities overreacting to the houseless situation that is ongoing, and they're hiding behind the premise that they're providing much needed care and shelter and slowly taking us back to institutionalization. And so as a network, we continue to have discussions on how we can best respond to this because it's difficult when the resources are unavailable to say this individual should not be institutionalized and they should be able to access the resources in the community, but the communities aren't providing those resources. And just recently, we heard the governor of California indicate, "It's up to the communities. It's up to the counties to provide these services," but the counties are saying, "We don't have the money or we don't have the staff."

(01:42:13):

And so who gets caught in the middle? It's individuals with a mental health diagnoses. Who gets caught in the middle when a youth who has finished whatever detention time they were supposed to serve, and they are unable to go back into their community because their particular community doesn't provide the services that they need. The child welfare system is also not providing services as required to use in foster care that also have a disability or disabilities. Why is that? You are charged with ensuring that children and youth placed in your care can reach their full potential by providing them the services that they need. And we're not doing that. Our educational system is not providing the services that we need to ensure that a youth with a disability or a 504 plan can access the educational environment equitably and equally like other students. And so time and time again, we're failing to fund what I call the front end of the system and focusing on the backend, which is putting folks in jails and prisons or putting them in an institution. That makes me angry 24/7.

(01:43:34):

And we need to stop that. And it starts with providing services to families to keep families together, to providing services to children and youth to make sure that they reach their full potential so that as they're growing up and they're entering society and in jobs, they have everything they need to be successful. But when we have marginalized communities not being serviced the way that they should be serviced, then ultimately, we as a P&A have to step in and help them out to ensure that we're fighting to make sure that those services are being provided.

Keith Casebonne (01:44:14):

Well, and it's a shame that different jurisdictions are pointing fingers at each other, but in the meantime, people are getting institutionalized. They're being abused, they're being hurt, their rights are being denied or not respected. But you did mention that the P&A's role is so clear to come in and help with those things and step in. So tell us a little bit about how P&A's are uniquely positioned to address present day abuse and neglect.

Marlene Sallo (01:44:40):

So we have what we call Access Authority, which other disability rights organizations do not have, and that's mandated by the statute. And so we have this authority to speak to individuals with disabilities to provide them with information, training, referrals to programs, and to also provide

them with information about their own rights so that they are empowered to speak up for themselves. But we also, as part of this access authority, we have the ability to monitor a service provider or facility to ensure that they are complying with the rights and the safety of individuals with disabilities. And we also use this access authority to make sure that when we come in and we monitor a facility, we're looking at the areas that are open to the public, where individuals with disabilities would have access to ensure that those areas are truly accessible to individuals with disabilities.

(01:45:43):

And that authority also allows us to investigate allegations of neglect and abuse of people with disabilities. It allows us to extend to monitoring or investigating abuse and neglect allegations about a particular facility or service provider. And in addition, as part of that beautiful access authority, if we go in, we're monitoring, then something comes to our attention that then triggers an investigation, and now we need to get more information, then this authority also gives us access to records. Now, there's two ways of accessing records. We can either get consent of the individuals directly affected, but in certain situations, in cases where we're conducting an abuse or neglect investigation, we can access those records without getting individual authority because it's at the level that truly requires us to get the full picture of what is going on so that then we can come in and make a determination if the P&A chooses to do so, to file a lawsuit, to make sure that we can take care of the abuses that is going on.

Maddie Crowley (01:46:54):

Yeah. And when I got started at the P&As and when people learn about the network, I think the access authority is such, it cannot be overstated, the power that that has, especially as we call back to our history of Willowbrook and Olmstead and just a deinstitutionalization movement at a whole, because that is essential to holding the institutions and folks in power that have reinforced the discrimination, abuse, neglect, et cetera, of people with disabilities. So I think you laid that out so wonderfully and clearly for folks to understand. And for people listening, we really encourage you to look into your state's P&A, and the extent that they're able to use that. I think it goes so far beyond what other civil rights orgs can do, what other disability orgs can do, and I think it really showcases the magnitude of the harm that has been done to the disabled community because of the magnitude of power that it offers, the P&A network. So I think it's just an incredibly important part of the work that we do.

Marlene Sallo (01:48:14):

Right. It's about holding people accountable. Because if you don't hold them accountable, then they're like, "I can get away with it. I'm going to continue getting away with it." And nine times out of 10 individuals that are directly affected by these violations may not have anyone that they can reach out to ask for assistance. And so we are there to be that voice and to be that connection for them.

Maddie Crowley (01:48:40):

Right. Well, as you laid out throughout this discussion, timing our own movement history as it relates to civil rights and other marginalized folks, is there any other parts of our history that seem important to highlight and bring to the forefront, especially as we move forward as a network and continue this work in the coming years, decades, et cetera?

Marlene Sallo (01:49:11):

One of the things that I've set out to do as the new ED here is to really have conversations with organizations and individuals that don't work within the Disability Rights Movement or the sphere to help them make that connection, that disability rights is about all of us. And to help them understand that the disability rights movement is so synonymous with the Civil Rights Movement, right? Because when they think civil rights, they don't think about us and they should. And so what I always say to them is, "Remember that both movements technically we're looking for the same outcomes. We're both fighting for equality. So we're both challenging systemic barriers and seeking to dismantle discriminatory practices. We're both into grassroots activism. We both held protests. We have both held sit-ins. We both hold advocacy campaigns to raise awareness." So it's that collective action that took place in the Disability Rights Movement and the Civil Rights Movement that now calls for us to join forces to continue that collective action.

(01:50:22):

But we are also both using a legal framework. Both movements have always sought legal protections to enforce the rights of marginalized communities. And we have both sought a cultural shift because there needs to be greater recognition of the rights and the dignity of all marginalized individuals. And we both have common goals. And what are those goals? We both want equity, justice, equal rights, and social change. And so we continue to achieve that. But along the way, we have all realized that it is important to not leave anyone behind. So members of marginalized communities, we need to lift their voices up. We need to lift the voices of people of color with disabilities, our trans and gender non-conforming sisters and brothers with disabilities, people who are houseless with disabilities, people who are incarcerated with disabilities, and even immigrants with disabilities. We are all part of the same humanity. That's it, right? We're part of humanity. And so we need to lift their voices up and make sure, and we do this every day as a network, that we're lifting everyone's voice and we're seeking equality and equitable treatment for all and not just some.

Keith Casebonne (01:51:51):

I think that's a wonderful path, a wonderful framework moving forward. And it's always been remarkable to me how the movements have been separated. I've never understood that because it doesn't make any sense to me. And when you think of just how many people in our country in the world identify with a disability, we're talking one in every four to five people. That's a snapshot of humanity. It includes everybody of so many other backgrounds and beliefs and identifications and identities.

Maddie Crowley (01:52:33):

Sorry, I would just even jump in to highlight just how intersectional parts of the Disability Rights Movement organizing was. When you think about the 504 sit-ins and how the Black Panthers and other religious and LGBTQ groups came in to provide aid, to bring food, to provide communication and blankets for, let's acknowledge the longest nonviolent sit-in American history, the 504 sit-ins that is cross movement organizing that is intersectional work. But it's a matter of telling that full history and continuing that cross movement organizing beyond the gains and the goals and the achievements of getting 504 regulations ... beyond getting ADA or Olmstead and these things actualized is a continuous effort. They say advocacy or activism is a verb, and it's something that you continue to do. You can't just do it in moments. And I think this whole conversation really is

such a testament to just the core values of disability justice and disability rights as it continues throughout the next decade of the network's work.

Marlene Sallo (01:53:57):

Absolutely. And beyond, let's hope that we're there in perpetuity because it's needed. It's needed. It's absolutely needed.

Keith Casebonne (01:54:06):

It is. And that will not be changing anytime soon.

Marlene Sallo (01:54:12):

No.

Keith Casebonne (01:54:12):

It is needed.

Marlene Sallo (01:54:13):

We're here to fight back.

Keith Casebonne (01:54:14):

That's right. That's right. Marlene, thank you so much for spending some time with us and talking about this really interesting and unique history, but yet with so many parallels to other civil rights movements, as you've mentioned, and it's great to have you leading the way with the National Disability Rights Network right now. We're really thrilled to have you here. And thanks so much again.

Marlene Sallo (01:54:37):

It's an honor.

Keith Casebonne (01:54:38):

Yeah, it's an honor to have you on our show. We really appreciate it. Thanks so much.

Marlene Sallo (01:54:43):

Thank you. I really appreciate being here with everyone today.

Maddie Crowley (01:54:48):

Thank you, Dr. Bronston and **Marlene Sallo** for being on the podcast. It was truly an honor to talk with both of you about such an important topic, and we're both so incredibly grateful for the time and energy you took to talk with us.

Keith Casebonne (01:55:01):

Yes, indeed. And so for those interested, we've linked to the things mentioned in the episode in the show notes. We will be back in two weeks with an episode on technology and ableism.

Maddie Crowley (01:55:13):

Yeah. So make sure to subscribe to the podcast wherever you're listening so you get episode notifications when new ones come out, and we're on all the podcast platforms, Apple Podcasts, Spotify, Google, Amazon, you name it. And you can also listen or read the transcript of each episode on our website. So visit disabilityrightsflorida.org/podcast to access those transcripts.

Keith Casebonne (01:55:37):

Yes, indeed. And again, thanks always for listening. Please email any feedback, questions, or ideas about the show to podcast@disabilityrightsflorida.org. See you again in two weeks.

Announcer (01:55:48):

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