

Interview Date: August 19, 2007

Subject: Dr. Michael Wilkins: Medical Internship/Residency Program – 1967 United States Public Health Service, Physician, Willowbrook State School

On August 19, 2007, CSEA interviewed Dr. Michael Wilkins, who formerly served as a staff physician at the State operated Willowbrook State School for the Mentally Retarded, located on Staten Island New York in the late 1960s and early 1970s. Wilkins came to Staten Island, New York in 1967 to complete his medical residency as a pediatrics intern to fulfill his military obligations to the US Health Service. Wilkins notes that at that time, the employee union CSEA, was not a strong presence at the facility, and it did not effectively promote workplace safety and training guidelines for employees.

Wilkins discusses how he became aware of and eventually exposed the deficient and inhumane circumstances of Willowbrook State School, which at the time was the largest institution for the mentally retarded in the world. Dr. Wilkins strongly asserts that had there been stronger union representation and presence, it could have helped better address the conditions at Willowbrook.

Wilkins speaks fondly of his friend Dr. William Bronston who recruited him to work at Willowbrook. Wilkins paints a sorrowfully agonizing picture of conditions at Willowbrook. Wilkins speaks in great detail about the regimented institutional model that was employed at Willowbrook. Wilkins speaks about how employees came to terms with their working circumstances and his own justifications and growing disillusionment. Wilkins talks frankly about the challenges of helping families and his efforts to educate them about the opportunities to seek better care for their loved ones.

Wilkins describes the circumstances that led to his firing from the facility as a result of his community activism in the wake of Governor Nelson A. Rockefeller's proposed budget cuts for the facility in 1972. Wilkins details his friendship with local WABC-TV New York newsman, Geraldo Rivera, and how he got Rivera to come to Willowbrook and document the conditions. Wilkins reflects on bringing Rivera into Willowbrook on multiple occasions in order to document and expose those conditions. The television reports created a storm of public controversy, sparked a series of legal proceedings and eventually led to numerous changes in the system.

Wilkins also explains that the lessons learned from this experience at Willowbrook provided the foundation for his continued community activism and professional awareness of the problems facing the mental health community.

Key Words

Benevolent Society

Community Organizing

CSEA

Department of Social Services

Developmentally Disabled

Shop Steward

Staten Island

Staten Island Advance

Union Shop

United States Public Health Service

Willowbrook State School

Key People

Dr. Jack Hammond

Dr. William Bronston

Geraldo Rivera

Jane Curtain

Nelson A. Rockefeller

Robert F. Kennedy

Ronald Reagan

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CSEA INTERVIEW

of

DR. MICHAEL WILKINS

August 19, 2007

1 THE INTERVIEWER: Good morning.
2 This is Saturday, August the 18th, 2007 and we are
3 in New York City and we are speaking with Dr.
4 Michael Wilkins and, Dr. Wilkins, I wonder if you
5 would tell us a little bit about your background.

6 DR. WILKINS: Well, I'm a medical
7 doctor. I'm from Kansas City, Missouri, and in
8 1967 I came to New York to do my internship and
9 residency and complete my military obligation in
10 the United States Public Health Service on Staten
11 Island and as a result of being on Staten Island
12 got familiar with Willowbrook State School, which
13 at that time was the largest institution for the
14 mentally retarded in the world and a very large
15 presence on Staten Island where I was living, and
16 after I got out of the United States Public Health
17 Service, I was there for three years. Then for a
18 year and a half I was employed at Willowbrook.

19 THE INTERVIEWER: What were the
20 circumstances that brought you to work over there?
21 Were you attracted to the kind of work that you
22 were going to be doing?

23 DR. WILKINS: I was and my good
24 friend, Bill Bronston, was already working there

1 when I was an intern on pediatrics.

2 At the hospital where I was an
3 intern they took us to Willowbrook to show us a
4 variety of genetic abnormalities. Willowbrook was
5 a repository of many genetic abnormalities and
6 they had a way that we could see them, having an
7 opportunity to visualize these people so that we
8 could recognize them in the future because they
9 were all collected there at Willowbrook and that
10 was the way we all got familiar with Willowbrook
11 and I told Bill about this place.

12 And Bill had an interest -- Bill
13 Bronston was a medical doctor, had an interest in
14 developmental disabilities, or mental retardation
15 as it was called in those days, and actually
16 became employed there and was coming home and
17 telling me stories about the conditions there that
18 were unbelievable, unbelievably bad, and so we
19 went to work there largely with a view to try to
20 understand the place and see if it could be made
21 better, if we could play a role in that.

22 THE INTERVIEWER: Okay. Tell us
23 more --

24 DR. WILKINS: The circumstances were

1 extremely adverse. The place was extremely
2 crowded. It had been built for 2700 individuals
3 and 5700 were living there. There would be large
4 rooms, dayrooms, where in my building 70
5 mentally-retarded people would be congregated in
6 one large dayroom with nothing to do, just sitting
7 on church pews or in some dayrooms not even having
8 church rooms but plastic chairs. One or two,
9 three at the most, attendants to take care of
10 these people. Common bathrooms with no privacy.

11 No inmate there, and I call them
12 inmates because I believe it was more like a
13 concentration camp or a prison than a health care
14 facility. No inmate had any possessions that they
15 could keep themselves. They had small, little
16 box, wire box or sometimes they were in wooden
17 boxes where their clothes and their possessions
18 were kept. They couldn't possibly have more than
19 that because the crowding was so great. There was
20 just no room to keep their stuff, so they were
21 floatin', as human beings, floating without any
22 sense of identity.

23 They were in a mass of other people
24 and they couldn't be kept clean, they couldn't be

1 fed decently, and therefore the medical conditions
2 that we were asked to take care of, because this
3 was a, quote, medical model, we were the doctors.
4 That was the way this place was justified, as
5 being a State school and a place where they could
6 be taken care of as -- by doctors, but still the
7 conditions there created chaos, and so there was
8 no progressive medical care. There was just
9 custodial care.

10 These people were brought to
11 Willowbrook to die there and they would be brought
12 sometimes as a young child and -- most of the time
13 and they would stay there without services,
14 without goin' to school, without training, just
15 rocking in a big empty room with other --
16 surrounded by other mentally-retarded people. It
17 was chaotic and disorienting for somebody that
18 would first go there.

19 THE INTERVIEWER: Now you said that
20 you had some warning that there were some
21 intolerable conditions before you actually went
22 over to work, but on a personal level what's it
23 like to walk into a place like this and to try to
24 adjust yourself to these dysfunctional

1 circumstances?

2 DR. WILKINS: The first thing that
3 assaults you when you walk in the building is the
4 smell and that sets the tone for the whole
5 experience. The smell is the smell of decay and a
6 mixture of sweat and feces and lack of being
7 cleansed in large numbers of people and it
8 permeated the building and so you open the door
9 and you step back and then you have to walk into
10 it.

11 And then on the outside of the large
12 dayrooms would be the medication room where the
13 nurses would stay. The nurses were at a higher
14 level than the attendants. In the dayroom the
15 attendants would be in these large rooms with the
16 inmates.

17 And so for a young doctor coming out
18 of an internship and a residency where there were
19 clean hospitals that smelled good, it was a
20 starkly different and depressing environment,
21 ultimately depressing, ultimately depressing. I
22 mean you'd go in your office and you'd say, what
23 am I doing here? What's going on here? What
24 chance do I have of making these people in any way

1 better?

2 THE INTERVIEWER: What -- how do you
3 come to a conclusion to stay and continue there
4 then?

5 DR. WILKINS: Hopin' that you can
6 make it better and realizing that you can't do
7 that without beginning to try to change the
8 underlying conditions.

9 THE INTERVIEWER: Tell me more about
10 who the clients of this facility were? What types
11 of individuals, where did they come from?

12 DR. WILKINS: They came mostly from
13 New York City. It's been called the Big Town's
14 Leper Colony where parents of mentally-retarded
15 people had no community services. They couldn't
16 keep their kids at home unless they were
17 independent -- had the independent funds to hire
18 people to take care of them. There were no group
19 homes for the retarded. There were no special ed
20 classes. There were no facilities where
21 developmentally disabled people could be serviced
22 in the community so they could stay with their
23 parents and the parents would get burned out.

24 They would be struggling to -- you

1 know, one of them would have to stay home with
2 this child in order to keep the child out of the
3 institution. If they didn't have the money, if
4 they were a single parent, there was just no way
5 they could avoid institutionalizing their child,
6 and there was actually a waiting list and the
7 physicians, community physicians, would recommend
8 institutionalization in those days.

9 THE INTERVIEWER: And what was the
10 range of developmental disabilities that you saw
11 among the residents?

12 DR. WILKINS: From severely retarded
13 people, the ones with what we call an encephali
14 where the actual -- you know, their head is very
15 small and they just have very little brain
16 function and they're not capable of doing anything
17 other than really eating and carrying out their
18 vegetative functions to kids who could talk to you
19 and had obvious ability to interact with me and
20 wanted out and were aware that they were in a bad
21 place.

22 They could watch TV and see what
23 real life is and so there was a whole range from
24 severely and profoundly mentally-retarded

1 individuals to mildly retarded individuals who
2 were, by the way, kept there as working boys and
3 working girls and made to mop the floors and
4 prepare the meals and do the things that needed to
5 be done to keep this concentration camp going.

6 THE INTERVIEWER: And was there any
7 kind of range of care that was provided or was it
8 pretty much one size fits all that everybody,
9 regardless of your ability level, got the same
10 treatment?

11 DR. WILKINS: No, there would be
12 different levels of treatment. Some of the higher
13 functioning individuals would be sent to classes.
14 Probably ten percent of the residents at
15 Willowbrook would be in classes -- of the school
16 age children would be in classes. There was a
17 model vocational program where they would teach
18 woodworking, but none of those people very got
19 discharged from Willowbrook because they got more
20 money if they had more residents and these higher-
21 functioning ones were easier to take care of and
22 actually could be working within the institution
23 so -- but there were -- I have to say that for the
24 severely and profoundly mentally-retarded people,

1 they were simply kept, you know, rocking and with
2 no services whatsoever, and the few services that
3 they had were more reserved for the more higher-
4 functioning individuals.

5 THE INTERVIEWER: So it was
6 basically more like a warehousing of these
7 individuals.

8 DR. WILKINS: It was a warehousing
9 deal.

10 THE INTERVIEWER: Can you tell me
11 more about the people who worked at the facility?
12 What were the types of individuals and the jobs
13 that they were performing?

14 DR. WILKINS: The bulk of the
15 individuals were attendants who were the
16 front-line workers out there in the dayroom,
17 working with the inmates, and their job would be
18 to try to bathe them and the method of bathing
19 would be to get six or eight of them together in
20 the shower room and get the hose and hose them
21 down and they would be squatting there and water
22 would be run over them. Keep them clean. For the
23 incontinent ones they would have to clean up after
24 them. For the ones that were continent they would

1 have to usher them back into the bathroom, keep
2 them clothed, because if their clothing got dirty
3 they would have to try to change their clothes,
4 try to just police them.

5 Because there would be, in my
6 building, 70 individuals milling around and there
7 were four dayrooms in my building, and so there
8 was a dayroom for the severely and profoundly
9 retarded in which some of these kids would be on
10 the floor and they would be kept in a
11 straightjacket because otherwise they would
12 scratch themselves or assault other patients and
13 they would just be rocking on the floor, and
14 others would simply be sitting motionless. The
15 employees would have to train these -- try to
16 train them to not move around and not make a fuss
17 because it was so much easier to take care of 70
18 people if they just don't move around very much.

19 And then there was a higher-
20 functioning room and there were four levels and
21 each was at a different functional level. One was
22 for people who were blind or many of them had
23 autism and weren't that really retarded but just
24 were autistic and so they would have employees who

1 would mostly be disciplinarians and lead them and
2 pick out ones who could work in their own right,
3 so those were the attendants and they were many
4 good people.

5 I want to emphasize that they
6 certainly weren't bad people. They were in an
7 environment where it was pretty impossible to be
8 functioning in any good way and I felt that
9 myself, but to get back to your question about
10 what kind of employees there were, well then there
11 were licensed practical nurses and they were
12 mostly medication givers.

13 These were heavily- medicated people
14 and they didn't need to be medicated -- they
15 wouldn't need to be if they weren't in that
16 building, but in order to contain them and lower
17 their energy level they would be given strong
18 tranquilizers. Some of them had seizure disorders
19 and their seizure medication would have to be
20 regulated.

21 Then there would be a building
22 supervisor. Sometimes that would be a person with
23 a nursing degree, but in my building it was a guy
24 who had no nursing background. He was just, you

1 know, a management guy. He was the person that
2 would answer to the administration building and
3 carry out their orders. And then there were
4 housekeeping people to -- in charge of cleaning
5 up, but mostly they would utilize the inmates to
6 do that job.

7 And then there were a smattering of
8 recreation therapists. They would take a group of
9 ten people at a time and they would walk around
10 the grounds of Willowbrook to get them outdoors.
11 There was -- there were some school teachers
12 because some of these kids would be going to
13 classes, so that was the kind of place it was.

14 THE INTERVIEWER: Was there a
15 hierarchy to the staff structure?

16 DR. WILKINS: Yes. The
17 Administration had a large building, a multi-story
18 building. It was shaped like a cross and that was
19 the first building you saw when you drove onto the
20 grounds, and the grounds were plush. They were --
21 it was a very big grounds and treed and a nice
22 rural -- semirural atmosphere on Staten Island
23 with 27 buildings that housed inmates and probably
24 an equal number of buildings that performed other

1 functions and so the structure was that the
2 Administration was the head of the hydra. You
3 know, they were the brains of the outfit and they
4 would give the orders.

5 The structure for the shifts, who
6 would show up, would be designed by the building
7 supervisor and okayed by the Administration
8 Building. They had some professionals such as
9 social workers. They had a Department of Social
10 Service which I think had seven social workers for
11 the entire institution with 5,700 clients and
12 about three psychologists, and their job mostly
13 was to do intelligence testing. They would test
14 these people when they were admitted to try to
15 grade them to see how much funds they could get
16 from the funding agencies.

17 But the low person on the totem pole
18 was the attendant and, again, the point person and
19 they would be completely taking their orders from
20 the building supervisor and to a lesser degree
21 from the licensed practical nurses.

22 THE INTERVIEWER: Did you experience
23 typical days? I mean were your days typical or
24 were they always different?

1 DR. WILKINS: There were typical
2 days. It was a pretty regimented place. I had
3 responsibility for Building 6 and most of the time
4 Building 5 and I would go there and the first part
5 of the day was given over to handling any medical
6 emergencies or situations that had developed
7 overnight or since I had last been there, and
8 these clients would be brought out to the
9 treatment room and I would see them and most of
10 the time it would be cuts, scratches, bruises,
11 trauma from other patie...I really didn't know
12 from who, but that would be a large part of it.
13 There would be people who were losing weight,
14 people who were having uncontrolled seizures or
15 uncontrolled behavior problems and that was the
16 bulk of it, so then that would be the morning.

17 And then in the afternoon I would be
18 trying to organize a care plan meeting in which we
19 would focus on one individual and see what
20 services would be good for them and what services
21 they were getting and what the results of those
22 services were. That was a new thing. I mean most
23 of the time it was a custodial warehousing
24 operation and no one much thought about that

1 because there was so little chance that the
2 clients would ever be discharged from the
3 institution, but in order to just meet medical
4 standards, one had to justify what was going on
5 and in some way document what should go on and
6 what the potential was.

7 THE INTERVIEWER: So -- I mean
8 you're looking at that as basically just a pro
9 forma exercise that you were going through?

10 DR. WILKINS: It was something that
11 there was really -- you could do that paperwork
12 without actually convening a meeting of the
13 attendants and the caregivers, but I was trying to
14 convene such a meeting so that we could think in
15 terms of developmental model rather than a
16 custodial model.

17 THE INTERVIEWER: Trying to deal
18 with the individual and provide some kind of plan
19 that's going to help that individual.

20 DR. WILKINS: Right. Try to create
21 the sense that the institution should be there to
22 respond to the needs of the individual instead of
23 the individual just conforming to what the
24 limitations of the institution were.

1 THE INTERVIEWER: Sure. You know,
2 tell me more about, you know, as you were trying
3 to do this and you mentioned that when you went to
4 work there you had some hope that perhaps you
5 could make a difference in bringing about some
6 better care. You mentioned earlier that there
7 were a lot of good people who were there.

8 What was the attitude among the
9 staff or tell me even more about the range of
10 attitudes among the staff about what they were
11 doing?

12 DR. WILKINS: The staff was a varied
13 group of people and in general it was a very
14 repressive atmosphere. The -- one of the most
15 important psychological needs would be to justify
16 what was happening to these people and so
17 everybody would justify it in their own way.

18 And I want to emphasize that the
19 essential justification was in the way the inmates
20 were defined and it was that a mentally-retarded
21 person doesn't really feel pain and it is not
22 possible to improve them, that they will not learn
23 and that they are a stain on their family. That
24 they should be taken out of their family for the

1 sake of the family. All of these justifications
2 were put on and all these stigmas were put on the
3 clients by the medical profession, my fellow
4 doctors and by the whole political setup in the
5 State which was to not provide services for the
6 development of these people but rather to just
7 take them and put them in an institution.

8 So that the employee is faced with a
9 dilemma. How do I justify this jail that these
10 people are in, so you had to figure that out in
11 your own mind and some people would respond by
12 becoming a disciplinarian and being proud that
13 they could establish discipline in their dayroom
14 and that all of their charges were sitting there
15 on the bench and they were rocking and they
16 weren't talking and they were not disturbing
17 anything.

18 Some would respond by having
19 favorites. They would -- there would be some very
20 compelling and wonderful responsive clients,
21 inmates, and they would treat them as their own
22 child and they would give them candy and bring
23 them clothes and try to be nice to them, not
24 necessarily to the other 67 individuals they were

1 in charge of, but they would isolate them as
2 having human qualities and the others as not.

3 Some would seek solace really in
4 drugs and alcohol and really would be just
5 displacing themselves from that environment, just
6 be there for eight hours. Then I'm outa here, you
7 know, don't talk to me. I can't deal with this.

8 And some would be genuinely good and
9 try -- good saints and try to help all of them and
10 work hard and so I think each person was left
11 without guidance and it was partially up to me to
12 try to give guidance and try to fight that sense,
13 that ideology that said that these inmates were
14 more like animals than humans.

15 I mean once you establish that
16 definition that this is a human being, the whole
17 game would have to change but that wasn't the way
18 mentally-retarded people were seen at that time.

19 THE INTERVIEWER: Even among the
20 medical staff.

21 DR. WILKINS: Correct.

22 MALE VOICE: Could we hold it a
23 second?

24 THE INTERVIEWER: Sure. Right.

1 (Brief pause.)

2 THE INTERVIEWER: Tell me a little
3 bit about the parents. You mentioned earlier
4 that, you know, for a lot of them they were
5 overwhelmed and that's -- there was even a waiting
6 list to try to get their children into this
7 facility. Were they aware of the conditions and
8 why would they put their children into these
9 circumstances?

10 DR. WILKINS: They weren't aware of
11 the conditions. They weren't allowed to go into
12 the dayroom or the sleeping room, and in the
13 sleeping room there would be 70 beds, cots, lined
14 up with about this much space (indicating) between
15 each cot. They weren't allowed to go back there.
16 When they would visit, and traditionally the
17 visiting day was on Sunday after...Sunday.

18 People would take the Staten Island
19 Ferry and they would then take the bus to
20 Willowbrook and they had to provide extra buses on
21 Sunday because they knew that people would be
22 going in large numbers out to Willowbrook, and
23 then they would come to the front door and they
24 would announce their presence and their child or

1 their family member would be brought to them,
2 would be dressed and cleaned and usually the staff
3 would know that this family member would be
4 coming, be kind of predictable, and then they
5 would take them out. Sometimes they would just go
6 walking on the grounds, sometimes they would take
7 them outside of the grounds and then they would be
8 gone for an hour or two and they would bring them
9 back.

10 That was how they came to the
11 institution and they were veterans of the system.
12 They -- this was the end of a long odyssey of
13 having born into their family a child with a
14 developmental disability and seeing the lack of
15 services available for this child and beginning to
16 feel guilty that you even had a developmentally
17 disabled child, that it was a bad report card from
18 God and it was somehow your fault and the system
19 wasn't providing you any services, so that was
20 more input that somehow you had to deal with all
21 of this.

22 And by -- and having talked to
23 doctors who at that time would recommend
24 institutionalization, would imply or just state

1 that the presence of a retarded child in the
2 family would be harmful to the other siblings, so
3 all of that baggage came with these parents, so
4 most of the time they were just downtrodden and
5 would come to visit. Their love was still there
6 although many of the clients at Willowbrook didn't
7 get visited, but many did and they would fiercely
8 love their family members.

9 And we began to see that these
10 family members contained the solution to the
11 problem; that they were the ones that understood
12 the problem and they were the ones that had the
13 connection and that they had just been not
14 understanding the potential of their child and
15 that once it was understood that this is an
16 individual that can grow and can learn and can
17 function better and can be happy, can exist in
18 society, they would feel differently and they --
19 we all became angry as we gradually learned more.

20 It was sort of a mutual learning
21 process. It wasn't as though I knew all of those
22 things when I first went to Willowbrook. I sort
23 of had a general sense that things weren't right,
24 but I didn't -- it was only as we educated

1 ourselves through this process that I began to
2 realize, hey, institutions are the opposite of
3 what a developmentally disabled person needs.
4 What they need is the love of their mom and dad
5 and their mom and dad need support to keep them at
6 home so that it's not much more difficult to raise
7 a developmentally disabled child than it is to
8 raise a so-called normal child.

9 And a developmentally disabled child
10 can bring a lot of spiritual benefits to the
11 family, so we all learned that together and as we
12 learned it we got more militant because
13 Willowbrook was getting worse. They were cutting
14 the budget and things and the services which were
15 bad when I went there got worse. Instead of
16 having two or three attendants with 70 individuals
17 they would have one as a matter of routine.

18 THE INTERVIEWER: M-m-m. You know,
19 I should have asked this earlier, but what was the
20 range of ages of the clients?

21 DR. WILKINS: They would be admitted
22 at a very young age, many of them. If they had
23 severe physical disabilities especially they would
24 be admitted at the age of one or two or three, and

1 so they had pediatric wards and as they got older
2 they would be moved to different buildings with
3 different age groups.

4 THE INTERVIEWER: And did it run
5 into an adult and elderly population?

6 DR. WILKINS: Yes. There were
7 buildings where there were elderly. Not too many
8 people lived to be very long there -- to be very
9 old there but there were buildings where there were
10 complete adults, and the building I was in served
11 kids from the age of about nine to twelve or
12 thirteen, and sometimes we would admit a nine-
13 year-old as a -- from the community new and that
14 was a wrenching experience because their parent
15 would be turning them over into this environment
16 that I knew was gonna feature trauma, physical
17 violence, rape and, I mean, it was just an
18 untenable situation on a personal level. It was
19 so hard.

20 THE INTERVIEWER: What was the role
21 of the Administration and what was the attitude of
22 them toward the circumstances?

23 DR. WILKINS: They were people who
24 had been in the field of running institutions for

1 a whole career. They were guys from their fifties
2 and sixties and they had been directors of
3 institutions. They typically would live on the
4 grounds of the institution. They were
5 institutionalized themselves.

6 They saw over the years that this
7 situation had been the same and that they felt
8 strongly that it wasn't going to change any time
9 soon and they, in fact, incorporated within
10 themselves this definition of a mentally-retarded
11 person being more like an animal that needed to be
12 contained in a building, taken out of their
13 family. They completely bought into that whole
14 ideology, and so they created this paradigm within
15 the institution of, okay, this is what we do.

16 We're the place where these people
17 are taken out of society, more like a prison model
18 and, you know, we're gonna run it efficiently.
19 We're gonna have doctors here. We're gonna have
20 nurses, but they couldn't open their mind to the
21 fact that maybe this wasn't the best environment.
22 They couldn't go there in their mind.

23 THE INTERVIEWER: And as you would
24 be concerned about the circumstances and trying to

1 make some adjustments were there any recep...you
2 know, any reception from the Administration to new
3 ideas?

4 DR. WILKINS: They -- I don't think
5 they were paying attention. We would rebel. We
6 would have a doctors' meeting once a month and the
7 other members of the medical staff, Dr. Bill
8 Bronston and I pretty isolated, really. We were
9 raising these issues of quality of care, the
10 issues of trauma and lack of adequate supervision,
11 and the medical staff was, you know, reacting
12 against our complaints about the system, so they
13 were -- they were not helpful. There were come
14 kind and decent people there, but as a group they
15 were there to protect the jobs and the institution
16 as it was.

17 The Administration was overtly just
18 wanting to maintain themselves as a bureaucracy.
19 They didn't want to lose clients. They wanted
20 to -- their view as and I think this came from
21 many, many years of their experience, were we are
22 bureaucrats and we are here to continue this
23 facility as it is and we were -- I don't think
24 that those of us who were trying to make change

1 were considered to be very important. Numerically
2 we were not and so they -- their response to us
3 was, you know, that we were a minor irritant but
4 that was about the way they looked at us as I
5 recall it.

6 THE INTERVIEWER: M-m h-m-m. Were
7 you aware of CSEA at that time? Did they have any
8 presence at the facility?

9 DR. WILKINS: CSEA was a union at
10 Willowbrook. At that time I honestly don't
11 remember that they had a structured presence. I'm
12 pretty sure in my building there was no union shop
13 steward or anybody to enforce the idea that these
14 employees shouldn't be forced to do more than
15 they're trained to do. They were -- the employees
16 could be made to speed up and so that one worker
17 would have to take care of 70 retarded people, an
18 entirely impossible job, and I don't think that
19 the CSEA was organized at that time in that
20 institution to speak up for -- against those
21 conditions, at least not that I recall in my
22 building.

23 THE INTERVIEWER: And do you
24 remember any attitude among the staff towards the

1 CSEA generally?

2 DR. WILKINS: You know, I don't. I
3 don't remember about the attitude toward the CSEA
4 actually.

5 THE INTERVIEWER: You mentioned
6 earlier that to a large degree the parents were
7 not aware of the conditions. What kind of
8 interaction was there between the parents and the
9 staff and did that pattern begin to evolve over
10 some time in your experience there?

11 DR. WILKINS: The relationship would
12 vary depending on the staff and the parent. Most
13 of the parents would try to find a staff member.
14 If this was a parent that visited regularly, they
15 would have -- you know, this would be a many-year
16 relationship and they would try to identify a
17 friendly face among a staff member that could tell
18 them a few words about how their relative or child
19 was doing, and so that would be what they would
20 seek.

21 In general, sometimes they would
22 succeed and sometimes though an impersonal staff
23 member would just present their child to them, but
24 if they possibly could they would want to bring a

1 little extra something for their child and be able
2 to give it to a human face that was kind and that
3 would take it and promise to make sure that their
4 child could utilize that for the rest of the week,
5 whether it be a pair of socks or a small toy or
6 something like that.

7 THE INTERVIEWER: Okay. And was
8 there awareness to any extent about the conditions
9 among elected officials or the outside community?

10 DR. WILKINS: I don't think so. I
11 know Robert Kennedy toured Willowbrook in I think
12 '67 or something like that, about five years
13 before -- four or five years before I was there
14 and stated that it was a snakepit at that time.
15 The local officials on Staten Island defended the
16 institution. There was a PR effort as people
17 would be brought to Willowbrook and a few model
18 buildings that had been funded with extra funds
19 from research grants and things, they would be
20 toured through there and then they would be taken
21 out and they didn't seem to answer or ask any more
22 questions than that. No local official ever did
23 while I worked there.

24 THE INTERVIEWER: Okay. Tell me

1 then how things began to change. How did your
2 attitude begin to change? What were some of the
3 actions that you took and how did events evolve?

4 DR. WILKINS: We started really
5 small. Dr. Bill Bronston and I and social
6 workers, a couple of real progressive social
7 workers that we were working with, started going
8 on Sundays and hosting weenie roasts outside of
9 our building because they had these pits were --
10 cooking pits, you know, outside, and we would have
11 an educational session about mental retardation
12 and what is appropriate in mental retardation on a
13 small level.

14 And at first just a couple of the
15 parents and their kids from my building came, but
16 when they saw that we were consistent and we kept
17 coming Sunday after Sunday, gradually more came
18 and at first it was an educational process. We
19 would have speech therapists saying, you know,
20 these kids can learn to talk and enunciate words
21 and communicate and we would have physical
22 therapists saying they really function much better
23 if their legs are -- if they have exercise
24 programs; occupational therapists about buttoning

1 and clothing themselves and how much more
2 efficient it is if you really train them so that
3 they can dress themselves and people who were --
4 ultimately we had a community meeting and this was
5 several months after we had gotten started, but
6 our organization was growing exponentially because
7 there was a hunger on the part of the parents to
8 get together and meet each other and it was a
9 therapeutic thing, sort of like a cancer support
10 group, I think, you know.

11 So it was growin' and it was
12 electric and so we sponsored a community meeting
13 where the World Health Organization's expert on
14 mental retardation was good enough to come to
15 Staten Island and he publicly said -- he was from
16 Scandinavia where they were very advanced in the
17 way they would treat mentally-retarded people.

18 He said this is not the way you
19 treat -- mentally-retarded people should be
20 treated. This is very primitive, very outdated.
21 They need community services. The parent --
22 family is what a mentally-retarded person needs.
23 Family. They need a mom and a dad that loves
24 them, that can teach them the way you teach

1 anybody, only those moms and dads need help
2 themselves because it is a more difficult job.
3 The kids learn more slowly. That's the only thing
4 about them. They learn more slowly. But you
5 can't -- the minute you take them out of the
6 family circle, things go downhill and that was a
7 revolutionary thing for all of us.

8 I mean I didn't know that when I
9 went to Willowbrook and so that changed things.
10 That was a focal point where we began to be
11 perceived within Willowbrook, and certainly by the
12 Administration, as a more significant enemy, I
13 think, because we were talkin' bad about the
14 institution and so, you know, this institution was
15 fostered largely on Staten Island by -- in
16 churches, people would volunteer there and they
17 supported Willowbrook, so any group of us that was
18 saying bad things about Willowbrook, we were
19 perceived as maybe being some kind of an enemy.

20 We weren't really wanting to be an
21 enemy but we had to say maybe we should think
22 about the possibility that this large institution
23 is doing harm and that changed what the parents
24 thought. We had to rethink a lot of our positions

1 activist kind of things after seven or eight
2 months, but there was an overlap. Some of the
3 parents that were coming to these meetings were
4 also involved in the Benevolent Society, but the
5 Benevolent Society had traditionally been sort of
6 bringing presents at Christmastime and things
7 like -- well-meaning things like that but not
8 coming with an idea that they're gonna change
9 anything.

10 THE INTERVIEWER: Okay. And as your
11 efforts began to attract more people and have more
12 interaction, what was the response on the part of
13 the Administration?

14 DR. WILKINS: Well, it was very
15 negative. The director of the institution, a
16 fellow by the name of Dr. Jack Hammond, who I
17 think was in his early sixties at that time, been
18 a long-time administrator, had been administrator
19 at several different institutions, was invited to
20 a meeting of the parents' group and this was after
21 Governor Nelson Rockefeller had cut the budget at
22 Willowbrook and there was a job freeze.

23 My job had -- I couldn't become a
24 permanent employee even though I'd been there for

1 over a year because they were freezing all
2 permanent positions in the case there would have
3 to be more layoffs, and there would be only one
4 attendant on a ward routinely and we had been
5 taking the parents in the back rooms. I mean that
6 was part of our parents' organization.

7 As the doctor in the building I was
8 the boss. I said you can come back here. Look,
9 this is what it is. So these parents were pretty
10 hot. They were pretty mad, and they insisted that
11 Dr. Hammond take a public stand against the
12 conditions at Willowbrook in this meeting, and he
13 stood up and said I'm not gonna do any such thing.
14 I've been in this business long enough to know
15 that that's not gonna do any good for these
16 patients or for me or for you.

17 We have to work within this system
18 and they banished -- they said get outa here. If
19 you're not gonna help us, you know, you leave, so
20 they made him leave and that was on a Sunday and
21 on the following Monday a memorandum was sent out
22 to each and every employee, because several of us
23 were at that meeting, saying that we couldn't go
24 to any more of the parent meetings.

1 And we did continue to go to the
2 parent meetings. We disobeyed that memorandum and
3 those of us who were not permanent employees, who
4 could be fired without cause, were fired. That
5 was what precipitated my getting fired and the
6 social worker in my building getting fired.

7 THE INTERVIEWER: Tell me more about
8 the circumstances of that. How did that actually
9 get executed?

10 DR. WILKINS: Well, they gave me a
11 pink slip. They -- the building supervisor just
12 said this is for you and, you know, you're fired,
13 and so that was it. I just had to clean out my
14 office and leave, but crucially they forgot one
15 thing and that is, I had a key and that key opened
16 every -- the doors, the locked metal doors in
17 every building of this big concentration camp, so
18 that was a big mistake on their part.

19 But the Administrator simply handed
20 me a pink slip and that was it. It was pretty
21 simple and I was pretty devastated.

22 THE INTERVIEWER: And you were
23 basically summarily dismissed at that point.

24 DR. WILKINS: Right.

1 THE INTERVIEWER: Literally right
2 out the door from that.

3 DR. WILKINS: And the social worker,
4 but her office wasn't really in my building, but
5 she -- there were two of us that were fired.

6 THE INTERVIEWER: Do you think that
7 it was because of your activism that you were
8 targeted?

9 DR. WILKINS: There was no doubt
10 about that.

11 THE INTERVIEWER: Okay. So what
12 happened after that?

13 DR. WILKINS: Well, I ended up, I
14 think within about 24 hours, I -- it just happened
15 that I was a friend of this local newsman in New
16 York named Giraldo Rivera and we were good enough
17 friends that he trusted me that the conditions
18 were bad and so he met me at a diner near
19 Willowbrook on a morning and, using our key -- he
20 was a, you know, a very different kind of
21 investigative reporter.

22 He was willing to go into this
23 institution. That hadn't been done except I think
24 there'd been a documentary called Titticut

1 (phonetic) Follies of an institution for the
2 mentally ill, but nobody had ever really gone into
3 an institution and put on public TV -- on TV a
4 direct viewing of the actual conditions in these
5 institutions. It was considered not ethical to do
6 that that time but we did.

7 Our view was, and we discussed it at
8 the time, that this was sort of like filming a
9 motor vehicle accident. This is a disaster. This
10 is a public situation. This isn't to be kept
11 under wraps, and so he was trusting me that the
12 conditions were bad and as he later said, it was
13 much worse than I had described, so what we did
14 was we went in the door, the back door, and
15 because they had such a low level of employee, I
16 mean sometimes we would be filming in a dayroom
17 and there would be nobody there.

18 They wouldn't even know we were
19 there, or there would be one employee who wouldn't
20 bother to go out and tell their boss we were
21 there. They supported what we were doing. It was
22 an unbearable situation.

23 THE INTERVIEWER: Did you go with
24 Giraldo?

1 DR. WILKINS: Yes. Yes. I would
2 open the door. We went together not just once but
3 many, many days, and I give him great credit for
4 grasping the importance of this and the true
5 situation instantly. When he first smelled it and
6 his crew first smelled it they said what, you
7 know, what is going on here? And so day after day
8 we kept returning and he vowed to return and he
9 did.

10 THE INTERVIEWER: Did the
11 Administration catch any wind that you were there
12 and doing this?

13 DR. WILKINS: Yes. I think that
14 same day I think they had called the television
15 station and threatened that they shouldn't put
16 that footage on the air, but the producer of the
17 show did.

18 THE INTERVIEWER: Did you -- I mean
19 when you were going in did you do this at the --
20 like the off-shifts or did you do just during the
21 normal --

22 DR. WILKINS: We just went during
23 the day.

24 THE INTERVIEWER: -- day?

1 DR. WILKINS: We went in the morning
2 during the day shift.

3 THE INTERVIEWER: M-m h-m-m. And
4 were the other staff receptive to you being there?

5 DR. WILKINS: Yes. We -- this was
6 really an interesting thing, that they -- no staff
7 member ever said leave, you can't do this. The
8 Willowbrook did start hiring security agents at
9 the gates, so instead of being able to just drive
10 in we had to park on the periphery and leap over
11 the stone wall and run down to where the buildings
12 were, but the employees themselves never did
13 anything but smile at us and wave and say, here it
14 is, you know?

15 They really were not wanted to
16 squash this information. I think an instinct in
17 them said, yeah, you know, let the people see this
18 stuff.

19 THE INTERVIEWER: I mean of course
20 you have this backdrop that the Governor has cut
21 the budget, that there are threats of layoffs that
22 are also coming into the mix.

23 Q

24 DR. WILKINS: Yes. So they -- and

1 that was a threat to them, and I don't think they
2 thought it could get much worse, I mean, so
3 they -- the administrators or the building
4 supervisors, it was an understood thing that you
5 wouldn't want them to know you were there and the
6 employees didn't.

7 I mean we filmed without any
8 interruption, without ever being evicted from any
9 building, because they -- we would be gone by the
10 time they knew we were there.

11 THE INTERVIEWER: And you did
12 actually go multiple times.

13 DR. WILKINS: Many, many times; for
14 months actually, but it did taper off. And then
15 at that point, I mean, this started having huge
16 ratings because the people of New York City were
17 shocked and they were watching it and so at one
18 point there were four different TV stations with
19 their cameras, not just Giraldo, so I mean I felt
20 like a Pied Piper. All I was doing, I had the key
21 and that was kinda my role. I was the guy that --
22 opening the door.

23 THE INTERVIEWER: So I mean you said
24 that Giraldo grasped the enormity of what was

1 happening here rather quickly. Was he very quick
2 to get this on the air or was there, you know, a
3 little bit of a lag to research it and be prepared
4 or was it something that it was just so visceral
5 that he took it immediately to air?

6 DR. WILKINS: He took it immediately
7 to air. It was the first day that we filmed, it
8 was on TV that night. He and his producer were
9 editing it and I was standing there and they
10 were -- they had a lot of footage and they were
11 editing it and they brought this to the attention
12 of the people of New York and he did have to go to
13 his producer and make the case to put it on the
14 air because the institution had called his
15 producer and said you better not put that on the
16 air. This is private. These are private lives
17 and you cannot film that and put that on the air.
18 These are our patients.

19 And so that was the dilemma and
20 he -- he is an attorney and he could cite
21 legalities about it and as a producer was an
22 attorney and Giraldo won because also it was clear
23 that this would get everybody's attention and that
24 it was a newsworthy item. It was truly news. It

1 wasn't some -- a private thing that you could say
2 was protected under people's privacy rights.
3 There was nothing -- they had no privacy there.

4 THE INTERVIEWER: Tell me on a
5 personal level, what were -- what was your
6 motivation in going to Giraldo and what did you
7 think would come of this?

8 DR. WILKINS: Well, we had been
9 trying to get people's attention. One of the
10 things that our parents' group knew was that if it
11 was only us, we probably wouldn't win. The public
12 had to support us but they had no way to know what
13 we were saying. We had leafleted outside of the
14 institution. When people would come in we would
15 leaflet and say please join us.

16 And we had a reporter from the local
17 Staten Island newspaper, the Staten Island
18 Advance. Her name was Jane Curtin and she was
19 very good and she came and did a multi-part series
20 on Willowbrook in which she pointed out that it --
21 that there were many deficiencies in that
22 institution and she went through it with us but
23 that didn't get anybody's attention because she
24 wasn't filming it.

1 I mean people basically cannot
2 believe it if you're just saying something is
3 atrocious. It's different from people seeing it
4 and so I think it was only when they saw it on the
5 film footage, you know, in their evening news and
6 they couldn't believe that this was their city and
7 that this kind of thing with young children in
8 straightjackets rocking and being covered with
9 feces was happening in their state.

10 THE INTERVIEWER: M-m-m. And what
11 beyond that was the official response from the
12 State and the Administration and how did that then
13 evolve?

14 DR. WILKINS: The State -- within a
15 few weeks Governor Rockefeller freed up \$9 million
16 in emergency funds and that was to, you know, buy
17 shoes and buy extra clothes because the inmates
18 were down to one change of clothes a day. If they
19 soiled these clothes they were naked the rest of
20 the day when this exposé hit, but then after that
21 they would have more than one change of clothes,
22 so it was cosmetic and they really thought it
23 would blow over.

24 I'm sure that was what was in their

1 mind, that if they just sort of made it so the bad
2 pictures couldn't be made that everything would be
3 fine, so that was their response. It was just
4 this is another blip in the chart, you know, but
5 these institutions aren't gonna change and we have
6 our own plan for these people and we're takin' a
7 cold shower here from this bad publicity but it's
8 gonna go away.

9 THE INTERVIEWER: M-m-m. But it
10 didn't. It continued.

11 DR. WILKINS: It did continue.
12 Giraldo made a -- with the help of Dr. Bill
13 Bronston, who had experience in California where
14 the State, even under Ronald Reagan, another
15 Republican governor, had provided community
16 services and begun to not admit patients to
17 institutions, and so in this documentary called
18 "Willowbrook, How It Is and Why It Doesn't Have to
19 be That Way" had the highest Nielsen rating of any
20 TV documentary in New York City up until that
21 time.

22 It made the point that, you know, it
23 doesn't really have to be that way and there can
24 be legislative changes that can begin to make

1 these changes and that they -- and that it's being
2 done elsewhere in the country and elsewhere in the
3 world.

4 THE INTERVIEWER: After all of this
5 happened, what did you personally do? Were you
6 continue -- did you continue to be involved with
7 this and what did you do professionally?

8 DR. WILKINS: I went to -- I was
9 pretty involved in this because it was getting the
10 attention of a lot of people and a lot of
11 organizations, the developmentally disabled on
12 Staten Island and elsewhere in the state of New
13 York, I would go and talk to them about my
14 experiences there and I was -- to earn money I was
15 working just as a physician in the emergency room
16 at Lincoln Hospital in the Bronx and then I went
17 back to Kansas City, actually.

18 About six months after this happened
19 I went back to Kansas City and finished my
20 residency. I just -- I didn't stay. I was sort
21 of -- I was frankly I think having post traumatic
22 stress syndrome. I was -- didn't like being fired
23 and I'm not a warrior. I am more -- I'm -- more
24 of a healer and a nurturing person and I don't

1 respond well to fightin' with people all the time,
2 so I was not ready to just fight the battle,
3 didn't feel like I could do it.

4 THE INTERVIEWER: M-m-m. Why did
5 you feel you had to do it?

6 DR. WILKINS: In the first place?

7 THE INTERVIEWER: Yeah.

8 DR. WILKINS: It -- because I was
9 responding to the situation. I mean you just get
10 desperate. I mean I think it was a desperate move
11 to put that thing -- to put it on TV and I -- it
12 was an act of desperation and it was completely
13 what the -- what our parent organization needed as
14 well, in retrospect, was to get the people's
15 attention and to get the people of New York on our
16 side instead of being ignorant about what was
17 going on there.

18 THE INTERVIEWER: M-m-m. From your
19 experience through this trauma can you -- what
20 have you gained in terms of insight and advice?
21 What kind of advice might you offer to others who
22 struggle with circumstances that they find
23 intolerable?

24 DR. WILKINS: Every situation is

1 different and to just -- as far as if you are in a
2 situation where you think the circumstances are
3 intolerable, there are all levels of that and you
4 have to analyze who are your friends and who are
5 your enemies and help to coordinate your friends
6 and organize them and create unity among them with
7 a clear vision of what the situation is and what a
8 positive correction factor would be and that does
9 require first education and coming together and
10 also having the originality to maybe figure out
11 that the situation is intolerable.

12 Because what was striking at
13 Willowbrook was that it was tolerable, even though
14 it was an intolerable situation. Because they
15 could define these inmates as being more like
16 animals than humans it was okay, and so to always
17 step back and say how am I defining this
18 individual?

19 I mean right now we've got two
20 million Americans in prisons, for example. We've
21 got over a million Americans in nursing homes.
22 Step back from that situation and say how are we
23 defining this? What's resulted in this because
24 that's a very high rate of institutionalization in

1 those two settings, so try to educate yourself
2 about the situation and try to see these clients
3 as people with potential and so those are some of
4 the lessons I think.

5 THE INTERVIEWER: Obviously as a
6 result of much of your effort and of course many
7 others we do have a better system of care today
8 for individuals with developmental disabilities.
9 Are you proud of your experience and what you did?

10 DR. WILKINS: I am. It varies a
11 lot. My nephew has a son with Downs Syndrome
12 named Michael, named after me, and he's my buddy
13 and he's four now and he lives in Kansas and he is
14 now in preschool and he's had the benefit of
15 physical therapy and this is all publicly
16 supported; physical therapy -- I mean my sister,
17 his grandma, took him on when his mom and dad had
18 to work and she's really done such a good job with
19 him.

20 The point is that in Kansas they've
21 got a pretty decent system of preschool services
22 and that's really important. So wherever you are
23 to study what system you have. It varies
24 tremendously from state to state and in New

1 York --

2 (End of Side A of tape.)

3 DR. WILKINS: (Continuing)

4 personally think it should be better for kids in
5 the preschool ages and I'm no big expert because
6 don't live in New York so I'm not saying that it's
7 perfect, but at least we don't have large
8 institutions and I believe in the concept of
9 normalization. Again I go back to the point that
10 staying in the home with the family, crucial, and
11 having an environment in which your family can
12 stay related to you, even when you turn 20 or 21
13 and you normally would move out of your home.
14 That's a normal situation. Move to a normal
15 environment, not an industrial environment but a
16 normal home-like environment with people who know
17 you and love you and not with big crowds but in a
18 small living situation and then you will continue
19 to have a human life.

20 And if you have good training and
21 education when you're young and people that love
22 you, you will develop. I mean there are so many
23 stories, even from my building. One Jimmy Jimenez
24 was a kid who lived on the unit where the blind

1 kids were and the autistic kids and he was a guy
2 that was a sculptor. He wanted to have aluminum
3 foil. If you would bring him a role of aluminum
4 foil, by the end of the day he would make
5 sculpture for you that was amazing but he was
6 nonverbal. He would just say silver paper, silver
7 paper. He would just sit there and make his
8 sculptures.

9 Okay. He got out of Willowbrook as
10 a result of the Consent Decree and he now has a
11 job and he lives independently. He's not having
12 to be supported by any agency whatsoever. The
13 point is that if you put somebody in an
14 institution where there's nobody around but other
15 developmentally-disabled people in a room with
16 walls and a TV and nothing else, you're not gonna
17 learn anything.

18 So it's that human -- I don't even
19 remember the question that you asked now. I'm
20 sorry.

21 THE INTERVIEWER: Well, I mean, the
22 point is that the awareness and the change even on
23 a national basis is largely traced to what you did
24 at Willowbrook.

1 DR. WILKINS: I hope so and I think
2 it was probably gonna happen. It had happened in,
3 you know, Scandinavia. This was so -- in
4 retrospect so self-evident, we were just, you
5 know, saying: Hello. This is the situation. It
6 is wrong and let's start changing this now. But
7 I -- I'm very happy that what we did, it just
8 happened that as a result of our organizing and my
9 getting fired and knowing Giraldo, it was a good
10 mix of circumstances that resulted in a lot of
11 changes.

12 THE INTERVIEWER: M-m-m. Well,
13 we've got a lot more to talk about with the
14 dynamics but I think that's a good break point and
15 thank you.

16 DR. WILKINS: You're welcome.

17 (Conclusion of interview of
18 Dr. Michael Wilkins.)
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