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
CSEA INTERVIEW

of

DR. MICHAEL WILKINS

August 19, 2007
THE INTERVIEWER: Good morning.

This is Saturday, August the 18th, 2007 and we are in New York City and we are speaking with Dr. Michael Wilkins and, Dr. Wilkins, I wonder if you would tell us a little bit about your background.

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

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

DR. WILKINS: I was and my good friend, Bill Bronston, was already working there
when I was an intern on pediatrics.

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

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

THE INTERVIEWER: Okay. Tell us more --

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

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

They were in a mass of other people and they couldn't be kept clean, they couldn't be
fed decently, and therefore the medical conditions
that we were asked to take care of, because this
was a, quote, medical model, we were the doctors.
That was the way this place was justified, as
being a State school and a place where they could
be taken care of as -- by doctors, but still the
conditions there created chaos, and so there was
no progressive medical care. There was just
custodial care.

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

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

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

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

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

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

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

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

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

They would be struggling to -- you
know, one of them would have to stay home with this child in order to keep the child out of the institution. If they didn't have the money, if they were a single parent, there was just no way they could avoid institutionalizing their child, and there was actually a waiting list and the physicians, community physicians, would recommend institutionalization in those days.

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

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

They could watch TV and see what real life is and so there was a whole range from severely and profoundly mentally-retarded
individuals to mildly retarded individuals who were, by the way, kept there as working boys and working girls and made to mop the floors and prepare the meals and do the things that needed to be done to keep this concentration camp going.

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

DR. WILKINS: No, there would be different levels of treatment. Some of the higher functioning individuals would be sent to classes. Probably ten percent of the residents at Willowbrook would be in classes -- of the school age children would be in classes. There was a model vocational program where they would teach woodworking, but none of those people very got discharged from Willowbrook because they got more money if they had more residents and these higher-functioning ones were easier to take care of and actually could be working within the institution so -- but there were -- I have to say that for the severely and profoundly mentally-retarded people,
they were simply kept, you know, rocking and with no services whatsoever, and the few services that they had were more reserved for the more higher-functioning individuals.

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

DR. WILKINS: It was a warehousing deal.

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

DR. WILKINS: The bulk of the individuals were attendants who were the front-line workers out there in the dayroom, working with the inmates, and their job would be to try to bathe them and the method of bathing would be to get six or eight of them together in the shower room and get the hose and hose them down and they would be squatting there and water would be run over them. Keep them clean. For the incontinent ones they would have to clean up after them. For the ones that were continent they would
have to usher them back into the bathroom, keep
them clothed, because if their clothing got dirty
they would have to try to change their clothes,
try to just police them.

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

And then there was a higher-
functioning room and there were four levels and
each was at a different functional level. One was
for people who were blind or many of them had
autism and weren't that really retarded but just
were autistic and so they would have employees who
would mostly be disciplinarians and lead them and
pick out ones who could work in their own right,
so those were the attendants and they were many
good people.

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

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

Then there would be a building
supervisor. Sometimes that would be a person with
a nursing degree, but in my building it was a guy
who had no nursing background. He was just, you
know, a management guy. He was the person that
would answer to the administration building and
carry out their orders. And then there were
housekeeping people to -- in charge of cleaning
up, but mostly they would utilize the inmates to
do that job.

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

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

DR. WILKINS: Yes. The
Administration had a large building, a multi-story
building. It was shaped like a cross and that was
the first building you saw when you drove onto the
grounds, and the grounds were plush. They were --
it was a very big grounds and treed and a nice
rural -- semirural atmosphere on Staten Island
with 27 buildings that housed inmates and probably
an equal number of buildings that performed other
functions and so the structure was that the
Administration was the head of the hydra. You
know, they were the brains of the outfit and they
would give the orders.

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

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

THE INTERVIEWER: Did you experience
typical days? I mean were your days typical or
were they always different?
DR. WILKINS: There were typical days. It was a pretty regimented place. I had responsibility for Building 6 and most of the time Building 5 and I would go there and the first part of the day was given over to handling any medical emergencies or situations that had developed overnight or since I had last been there, and these clients would be brought out to the treatment room and I would see them and most of the time it would be cuts, scratches, bruises, trauma from other patie...I really didn't know from who, but that would be a large part of it. There would be people who were losing weight, people who were having uncontrolled seizures or uncontrolled behavior problems and that was the bulk of it, so then that would be the morning.

And then in the afternoon I would be trying to organize a care plan meeting in which we would focus on one individual and see what services would be good for them and what services they were getting and what the results of those services were. That was a new thing. I mean most of the time it was a custodial warehousing operation and no one much thought about that
because there was so little chance that the
clients would ever be discharged from the
institution, but in order to just meet medical
standards, one had to justify what was going on
and in some way document what should go on and
what the potential was.

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

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

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

DR. WILKINS: Right. Try to create
the sense that the institution should be there to
respond to the needs of the individual instead of
the individual just conforming to what the
limitations of the institution were.
THE INTERVIEWER: Sure. You know, tell me more about, you know, as you were trying to do this and you mentioned that when you went to work there you had some hope that perhaps you could make a difference in bringing about some better care. You mentioned earlier that there were a lot of good people who were there.

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

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

And I want to emphasize that the essential justification was in the way the inmates were defined and it was that a mentally-retarded person doesn't really feel pain and it is not possible to improve them, that they will not learn and that they are a stain on their family. That they should be taken out of their family for the
sake of the family. All of these justifications were put on and all these stigmas were put on the clients by the medical profession, my fellow doctors and by the whole political setup in the State which was to not provide services for the development of these people but rather to just take them and put them in an institution.

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

Some would respond by having favorites. They would -- there would be some very compelling and wonderful responsive clients, inmates, and they would treat them as their own child and they would give them candy and bring them clothes and try to be nice to them, not necessarily to the other 67 individuals they were
in charge of, but they would isolate them as
having human qualities and the others as not.

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

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

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

THE INTERVIEWER: Even among the
medical staff.

DR. WILKINS: Correct.

MALE VOICE: Could we hold it a
second?

THE INTERVIEWER: Sure. Right.
(Brief pause.)

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

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

People would take the Staten Island Ferry and they would then take the bus to Willowbrook and they had to provide extra buses on Sunday because they knew that people would be going in large numbers out to Willowbrook, and then they would come to the front door and they would announce their presence and their child or
their family member would be brought to them, would be dressed and cleaned and usually the staff would know that this family member would be coming, be kind of predictable, and then they would take them out. Sometimes they would just go walking on the grounds, sometimes they would take them outside of the grounds and then they would be gone for an hour or two and they would bring them back.

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

And by -- and having talked to doctors who at that time would recommend institutionalization, would imply or just state
that the presence of a retarded child in the family would be harmful to the other siblings, so all of that baggage came with these parents, so most of the time they were just downtrodden and would come to visit. Their love was still there although many of the clients at Willowbrook didn't get visited, but many did and they would fiercely love their family members.

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

It was sort of a mutual learning process. It wasn't as though I knew all of those things when I first went to Willowbrook. I sort of had a general sense that things weren't right, but I didn't -- it was only as we educated
ourselves through this process that I began to realize, hey, institutions are the opposite of what a developmentally disabled person needs. What they need is the love of their mom and dad and their mom and dad need support to keep them at home so that it's not much more difficult to raise a developmentally disabled child than it is to raise a so-called normal child.

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

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

DR. WILKINS: They would be admitted at a very young age, many of them. If they had severe physical disabilities especially they would be admitted at the age of one or two or three, and
so they had pediatric wards and as they got older
they would be moved to different buildings with
different age groups.

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

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

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

DR. WILKINS: They were people who
had been in the field of running institutions for
a whole career. They were guys from their fifties and sixties and they had been directors of institutions. They typically would live on the grounds of the institution. They were institutionalized themselves.

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

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

THE INTERVIEWER: And as you would be concerned about the circumstances and trying to
make some adjustments were there any recep...you
know, any reception from the Administration to new
ideas?

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

The Administration was overtly just
wanting to maintain themselves as a bureaucracy.
They didn't want to lose clients. They wanted
to -- their view as and I think this came from
many, many years of their experience, were we are
bureaucrats and we are here to continue this
facility as it is and we were -- I don't think
that those of us who were trying to make change
were considered to be very important. Numerically we were not and so they -- their response to us was, you know, that we were a minor irritant but that was about the way they looked at us as I recall it.

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

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

THE INTERVIEWER: And do you remember any attitude among the staff towards the
CSEA generally?

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

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

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

In general, sometimes they would succeed and sometimes though an impersonal staff member would just present their child to them, but if they possibly could they would want to bring a
little extra something for their child and be able to give it to a human face that was kind and that would take it and promise to make sure that their child could utilize that for the rest of the week, whether it be a pair of socks or a small toy or something like that.

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

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

THE INTERVIEWER: Okay. Tell me
then how things began to change. How did your attitude begin to change? What were some of the actions that you took and how did events evolve?

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

And at first just a couple of the parents and their kids from my building came, but when they saw that we were consistent and we kept coming Sunday after Sunday, gradually more came and at first it was an educational process. We would have speech therapists saying, you know, these kids can learn to talk and enunciate words and communicate and we would have physical therapists saying they really function much better if their legs are -- if they have exercise programs; occupational therapists about buttoning
and clothing themselves and how much more efficient it is if you really train them so that they can dress themselves and people who were ultimately we had a community meeting and this was several months after we had gotten started, but our organization was growing exponentially because there was a hunger on the part of the parents to get together and meet each other and it was a therapeutic thing, sort of like a cancer support group, I think, you know.

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

He said this is not the way you treat -- mentally-retarded people should be treated. This is very primitive, very outdated. They need community services. The parent -- family is what a mentally-retarded person needs. Family. They need a mom and a dad that loves them, that can teach them the way you teach
anybody, only those moms and dads need help themselves because it is a more difficult job. The kids learn more slowly. That's the only thing about them. They learn more slowly. But you can't -- the minute you take them out of the family circle, things go downhill and that was a revolutionary thing for all of us.

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

We weren't really wanting to be an enemy but we had to say maybe we should think about the possibility that this large institution is doing harm and that changed what the parents thought. We had to rethink a lot of our positions
activist kind of things after seven or eight months, but there was an overlap. Some of the parents that were coming to these meetings were also involved in the Benevolent Society, but the Benevolent Society had traditionally been sort of bringing presents at Christmastime and things like -- well-meaning things like that but not coming with an idea that they're gonna change anything.

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

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

My job had -- I couldn't become a permanent employee even though I'd been there for
over a year because they were freezing all
permanent positions in the case there would have
to be more layoffs, and there would be only one
attendant on a ward routinely and we had been
taking the parents in the back rooms. I mean that
was part of our parents' organization.

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

We have to work within this system
and they banished -- they said get outa here. If
you're not gonna help us, you know, you leave, so
they made him leave and that was on a Sunday and
on the following Monday a memorandum was sent out
to each and every employee, because several of us
were at that meeting, saying that we couldn't go
to any more of the parent meetings.
And we did continue to go to the 
parent meetings. We disobeyed that memorandum and 
those of us who were not permanent employees, who 
could be fired without cause, were fired. That 
was what precipitated my getting fired and the 
social worker in my building getting fired.

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

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

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

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

DR. WILKINS: Right.
THE INTERVIEWER: Literally right out the door from that.

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

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

DR. WILKINS: There was no doubt about that.

THE INTERVIEWER: Okay. So what happened after that?

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

He was willing to go into this institution. That hadn't been done except I think there'd been a documentary called Titticut
(phonetic) Follies of an institution for the mentally ill, but nobody had ever really gone into an institution and put on public TV -- on TV a direct viewing of the actual conditions in these institutions. It was considered not ethical to do that that time but we did.

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

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

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

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

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

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

DR. WILKINS: We just went during the day.

THE INTERVIEWER: -- day?
DR. WILKINS: We went in the morning during the day shift.

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

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

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

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

Q

DR. WILKINS: Yes. So they -- and
that was a threat to them, and I don't think they
thought it could get much worse, I mean, so
they -- the administrators or the building
supervisors, it was an understood thing that you
wouldn't want them to know you were there and the
employees didn't.

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

THE INTERVIEWER: And you did
actually go multiple times.

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

THE INTERVIEWER: So I mean you said
that Giraldo grasped the enormity of what was
happening here rather quickly. Was he very quick
to get this on the air or was there, you know, a
little bit of a lag to research it and be prepared
or was it something that it was just so visceral
that he took it immediately to air?

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

And so that was the dilemma and
he -- he is an attorney and he could cite
legalities about it and as a producer was an
attorney and Giraldo won because also it was clear
that this would get everybody's attention and that
it was a newsworthy item. It was truly news. It
wasn't some -- a private thing that you could say
was protected under people's privacy rights.
There was nothing -- they had no privacy there.

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

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

And we had a reporter from the local
Staten Island newspaper, the Staten Island
Advance. Her name was Jane Curtin and she was
very good and she came and did a multi-part series
on Willowbrook in which she pointed out that it --
that there were many deficiencies in that
institution and she went through it with us but
that didn't get anybody's attention because she
wasn't filming it.
I mean people basically cannot believe it if you're just saying something is atrocious. It's different from people seeing it and so I think it was only when they saw it on the film footage, you know, in their evening news and they couldn't believe that this was their city and that this kind of thing with young children in straightjackets rocking and being covered with feces was happening in their state.

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

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

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

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

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

It made the point that, you know, it doesn't really have to be that way and there can be legislative changes that can begin to make
these changes and that they -- and that it's being done elsewhere in the country and elsewhere in the world.

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

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

About six months after this happened I went back to Kansas City and finished my residency. I just -- I didn't stay. I was sort of -- I was frankly I think having post traumatic stress syndrome. I was -- didn't like being fired and I'm not a warrior. I am more -- I'm -- more of a healer and a nurturing person and I don't
respond well to fightin' with people all the time, so I was not ready to just fight the battle, didn't feel like I could do it.

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

DR. WILKINS: In the first place?

THE INTERVIEWER: Yeah.

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

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

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

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

I mean right now we've got two million Americans in prisons, for example. We've got over a million Americans in nursing homes. Step back from that situation and say how are we defining this? What's resulted in this because that's a very high rate of institutionalization in
those two settings, so try to educate yourself
about the situation and try to see these clients
as people with potential and so those are some of
the lessons I think.

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

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

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

(End of Side A of tape.)

DR. WILKINS: (Continuing)

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

And if you have good training and
education when you're young and people that love
you, you will develop. I mean there are so many
stories, even from my building. One Jimmy Jimenez
was a kid who lived on the unit where the blind
kids were and the autistic kids and he was a guy that was a sculptor. He wanted to have aluminum foil. If you would bring him a role of aluminum foil, by the end of the day he would make sculpture for you that was amazing but he was nonverbal. He would just say silver paper, silver paper. He would just sit there and make his sculptures.

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

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

THE INTERVIEWER: Well, I mean, the point is that the awareness and the change even on a national basis is largely traced to what you did at Willowbrook.
DR. WILKINS: I hope so and I think it was probably gonna happen. It had happened in, you know, Scandinavia. This was so -- in retrospect so self-evident, we were just, you know, saying: Hello. This is the situation. It is wrong and let's start changing this now. But I -- I'm very happy that what we did, it just happened that as a result of our organizing and my getting fired and knowing Giraldo, it was a good mix of circumstances that resulted in a lot of changes.

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

DR. WILKINS: You're welcome.

(Conclusion of interview of Dr. Michael Wilkins.)