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DP

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TAPE: Tape 17

INTERVIEWEE: Thomas Scully, M.D.

INTERVIEWER: Eileen Barker

PLACE: DR. Scully's home, 1400 Ferris Lane

TRANSCRIPTIONIST: Dianne Fernandez

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**EB: We are going to pick-up with the Special Children's Clinic. You started at the Special Children's Clinic in?**

TS: I started at the clinic, the year I resigned as the Dean, which was in the fall of 1979. The reason I resigned is because I had surgery and I was recuperating. So I took several months of sick leave until the end of that year, through November and December. President Crowley appointed Ernie Mazzaferri acting dean. In January or February of 1980, (it was in the winter of 1980 early on), Mr. Desibio, who was the head of the State Health and Human Services, (or in those days it was Health, Education and Welfare) like the Federal HEW, called and said that he needed a physician to work at the Special Children's Clinic, which at that time was on California Road, near the corner of California and Arlington, behind the bank. It was in an old building on the second floor. He wanted a physician who would visit a couple of days a week and examine the children and give medical input. In those days most of child evaluations at Special Children's Clinic were done by Joan Edwards, who was a psychologist, or by people who were trained in speech pathology, audiology and physical therapy. Most of the children who were referred to the clinic there, mostly preschool children, had one or another mental or physical disability. At any rate, since I was still on the faculty of the medical school and a member of the department of pediatrics, I said I'd be happy to do that. I called Burt Dudding who was my chairman, (as a matter of fact I had hired Burt in 1978 to come and start the department of pediatrics when our conversion was on) and he said fine that will help off set some of your salary. I think we worked out a contract with the state Health Division that would pay, I'm guessing 40% of my salary and I would spend two days a week there. They would pay the money to the Medical School and then that would go into my salary. So some time in the late winter or early spring of 1980, I went and started working several half days per week evaluating children who were referred to the Special Children's Clinic. They came from hospital nurseries as young infants; they came from physicians (both pediatricians and general practitioners), referred by schools and preschool programs. A variety of ways in which children would be sent to a state agency, run by the state with state and federal dollars, essentially to evaluate children who had any kind of disability.

**EB: Who is Desibio?**

TS: Mr.Desibio, at the time had been working for the State Government as the director of the division of Health and Human Services. He subsequently left and went back to New Jersey where he was from. Larry Matheis took the job for a few years replacing Desibio.

**EB: So neither of those were doctors?**

TS: No, they were both administrators. They have degrees but they were administrators essentially running state agencies. Sometime that summer or early fall 1980 into 1981, they decided they were going to build a new Special Children's Clinic, along with a Children's Behavioral Services Center, right behind the medical school off of Valley Road. The state had property there and in the matter of a year or so I was very fortunate to be asked my opinion about how that Special Children's Clinic should look. I had my portion of the clinic designed so that I could bring medical students and pediatric residents. One of my agreements with Desibio and then subsequently with Larry Matheis, when he took over the job, was to be able to bring medical students and residents there. Remember at that time we had already started the third year clerkships, so we had clerks in pediatrics and we had already started a pediatric residency. So we had residents in pediatrics and I would then, as a part of my faculty duties at the medical school in the department of pediatrics would bring students and residents and teach them how to evaluate children with disabilities and handicaps. There would be everything from children with seizures, blind children, deaf children, small premature babies who had various birth defects. Basically the idea, under what was then a federal law, was trying to decide what special educational and medical needs these children had. Particularly those children, whose parents didn't have much in the way of health insurance. We needed to be sure they received adequate medical care. Occasionally, rarely, one of those children would have to institutionalized. But most of them, including a large population of Down's Syndrome children, (I'm guessing maybe fifteen or twenty), would come to the clinic and in addition to being evaluated by this multidisciplinary team they would also attend a preschool, which they were running at the clinic. In the new building, which has now been in existence since the early 1980's, they actually had play yards, preschools and they had programs where little infants could come and get help with learning the basics of walking, crawling, climbing, and speech. I've always been very supportive of the Special Children's Clinic. I did that for another four and a half years.

**EB: This wasn't a well baby clinic, was it?**

TS: No, absolutely no well babies. They were all children who had been screened by some health care person, a public health nurse or someone. We also saw children who were victims of child abuse. It was really a mixed bag of problems, but they were all children who had been sent there by some health professional or some school or someone because they had a problem and they needed an interdisciplinary team to help them. At the same time when I resigned as the dean, the Sierra Developmental Center, which in those days we called the Sparks State Hospital for the Mental Retarded, needed a physician part-time. The director there, who I knew, called and said, " I understand that you have resigned and you are going to be working at Special Children's Clinic." Could you come over and give us two or three hours a week to help, first of all, train our staff nurses and psychologists in the medical care of the mental retarded? These would be institutionalized children who live there and also take care of their medical needs. A lot of them would have convulsions and seizures and they needed medications. Many of them would get ear infections or pneumonias; some of them would have other health problems. So, I said, " sure." Actually, over the course of the next couple of years about half of my salary came from the State through Special Children's Clinic and through the Sierra Developmental Center which was the in-hospital home for the mental retarded. My agreement there was also to bring students and residents. I would take students and residents in pediatrics over there. That would give them an experience of what it was like for a child to be institutionalized.

**EB: That was a whole range of ages, wasn't it?**

TS: Yes, I would only care for those up to the age of twenty-one and there was another whole ward of adults who had been there for years. Many…

**EB: With Down's…**

TS: Everything, PKU, Down's, children who years ago had measles, encephalitis or meningitis or children who had had hydrocephalus and a variety of problems that fifteen, twenty or thirty years before lead to severe retardation. Long before we had much treatment for any of those things. So, I had patients who had been in the institution since they were infants or young children and were there fifteen to twenty years when I saw them. That was their home, they had become wards of the State. Some had been abandoned by their parents or had been turned over to the State through a court order. There was a lot of that.

**EB: It must have been a wrenching experience?**

TS: Yeah.

**EB: You were so immersed in it.**

TS: I was but, I remember telling you early when I was in medical school, going to the hospital for my OB experience in Albany, seeing for the first time, children with hydrocephalus. I think, part of being a pediatrician is not just taking care of the healthy, any body can do that, mothers can do that without you, but it's to help in the care of children with all sorts of special needs. So it was part of, I guess you'd say, a pediatrician's duty but also part of a pediatrician's skill and training. There are a lot of physicians who do not like to care for the mentally retarded. They are not comfortable with it. They are not comfortable dealing with the families who were suffering themselves. As you know it is devastating for parents or whole families to be told that they have a child who has a severe birth defect or a child who has severe mental retardation. I felt that I had an aptitude for it and I had a feeling for these children and at any rate, I did it and I enjoyed it. I did it for about two and a half years when I was approved for my sabbatical to go the Hastings Center in New York to study medical ethics. Just as an aside we can come back to that in a moment. From the summer of 1982, which would be about August, to June of 1983, I left those two jobs. I went on sabbatical to the Hastings Center in New York. Celia and I lived with her mother, who lived in New Rochelle where we were raised. I would drive over each day to the Hastings Center and my son and daughter-in-law stayed in this house in Reno with one of the youngest and they took care of the home. For that year while I was gone, Dr. Kay Walker, who had just finished her residency with us in pediatrics, took over those two positions and worked at the Special Children's Clinic and kept it going until I returned. Then in June of 1983, when I finished my sabbatical, I returned to Reno, and resumed my job. In the meantime Kay had found herself a job in Oakland where she wanted to be at the Children's Hospital. So, I then went back, part time, to the Special Children's Clinic in the summer of 1983. I did that up until a few months before my kidney transplant in the spring of 1987. As a matter of fact, I'd go there almost halftime for the next three and half years, when it was clear that I was going to have my kidney transplant, I was in renal failure. I was going to be on sick leave for about six months, which was in June of 1987. I resigned at the Special Children's Clinic, probably February or March of 1987 and have never been back since. Joanna Fricke took over when I left and she did it for several years. They found several other physicians who would take care of these children over the years. I guess, thinking about the actual timing, I probably worked at the Special Children's Clinic for about six years. January of 1980 to the spring of 1987 with the one twelve month hiatus in 1982-1983 when I went on my sabbatical to New York.

**EB: You didn't go back to the State Hospital?**

TS: No, when I came back from New York, I did not do that. As a matter of fact, I found another doctor in town who was finishing his residency in Internal Medicine, (I guess it was), and he was looking for some part-time work. So when I left in 1982 to go on my sabbatical, I recommended that he be hired. I never went back to the Sierra Developmental Center but I did come back and do Special Children's Clinic. By then I had returned from a sabbatical and with Burt Dudding's approval and subsequently his successor, Bob Bonar's approval. (Burt resigned as chairman of pediatrics in 1983 or 1984, maybe while I was on my sabbatical or shortly thereafter) Bob Bonar, We also had the approval of Bob Daugherty who was the Dean by then. I went on a part-time contract so that I could spend a year with Celia writing our book "Playing God". So when we returned from our sabbatical we started working on that book. I'd go to Special Children's Clinic a couple mornings a week, I would stay home a couple mornings a week and Celia and I would write. Literally we would write together side by side in her study next to the computer, and then I would do my teaching obligations and I would take care of the children in the Clinic.

**EB: Did you implement any of the ethics training that you had? At the medical school?**

TS: Yes we did. I will have to look that up. When I came back from my sabbatical in June of 1983, I put together a curriculum in medical ethics, which would be taught to the freshman and sophomore medical students. And as you know, at the University you have to go through a lot of committees to start new courses and you have to have an outline and spell out the objectives and all that. So, I did that. I think that next spring, maybe the spring of 1984, the curriculum committee, the faculty, and the Dean, (Bob Daugherty), and everybody concurred and approved putting in an ethics curriculum. I started in the fall of 1985 doing it maybe every other week for two semesters. There might have been six or seven, two hour sessions in the fall and six or seven, two hours sessions in the spring. It was for the sophomore medical students. The whole idea was to prepare them to be conversant with some of these ethical issues before they started their junior clerkships.

**EB: What kind of training would they get for the layman who will be interested in this kind of thing? What kind of training would they get in ethics? Not training, what kind of exposure?**

TS: Most of it prior to actually seeing a patient, because they didn't see many patients in a medical setting until they were Juniors and we wanted them to prepare for that. So what I did, and many other schools in the country have done this, along with the help of others and taking from various text books and manuals that other medical schools had used, I develop about fifteen case vignettes on paper, fairly complicated vignettes which would address various ethical issues. For example, issues of abortion, issues of in vitro fertilization, issue of withdrawal of life support, assisted suicide, euthanasia, and issues of withholding information from patients, truth telling, and confidentiality. All of these fairly important ethical issues, that they were likely to see in their third and fourth year and subsequently in their residencies, would be put in "paper cases". They would be given the cases in advance after some introductory lectures and a syllabus that I gave them and then they would be broken up into small groups, much like they do in other problems solving sessions at the school. These small groups would be expected to work out, on paper, their solution to whatever the problem was. Then they would come to class and I would randomly call on them. I wanted everybody to be prepared. I would randomly call on some representative of the group, and they would describe what they considered to be the ethical issue in the case. For example lets say, withholding of life support or taking someone off of a ventilator and allowing them to die in an intensive care unit. This is an emotionally difficult problem for any nurse or doctor to deal with. Then I would ask what were the ethical issues involved and how did they resolve those issues among their group? What conflicts did they have in their group? Who agreed and who disagreed with whatever the action would be? Then I would always force them to get off the fence and make a decision. What are you going to do? You can't sit around debating this for days. There is a patient dying there, a patient in need of medication, or there is a patient or a family in need of support. I would force them to make a decision and then I would challenge them. Why would you do this instead of that? Why would you do A instead of B? Then when it was all over I would give them some copies of relevant literature or similar cases that had been discussed in the literature by experts but I would force them to deal with the problem beforehand. So it was not a lecture course, I wasn't coming in giving them a set of answers because in many of these issues there are not clear-cut answers. There are acceptable answers that society will accept but they may not be clear-cut in all instances. Rather than come in and give them a lecture, you know these are the conditions, these are the problems, and this is how you deal with it. I would force them to use their own background, their own culture, their own religion, their own experience and their own gut feelings and then give them something to read afterwards which had been written by someone who had dealt with this kind of problem. Actually, that whole shelf (pointing to the library in the room) is filled with Hastings Center reports which follow this format of teaching, where experts in the country will write in and discuss how they would confront such an issue. Anyway, that is what we did and we are still doing it.

**EB: This was not for grade?**

TS: No, it was just pass/fail but they had to show up. They had to show up and participate. It was required in that sense, but I didn't give them an A, B, C grade if that is what you are asking.

**EB: Yeah.**

TS: No it was simply a pass/fail and frankly if you participated that was sufficient to pass. That was what it amounted to. The main thing was they had to show up and participate.

**EB: What was the different ethnic, cultural, religious mixes in these classes? Did you have any?**

TS: Oh, some hot and heavy arguments. Absolutely, very hot and heavy arguments.

**EB: How were those resolved? Because some people would know what was socially and medically acceptable but maybe their own background would preclude coming to this kind of a decision. Maybe not a religious issue but a cultural one.**

TS: Absolutely, there were some of those rather hot and heavy arguments and one of the principles of having an ethical discussion is permitting the other person to express their views and respecting their right to express them, while disagreeing vehemently with what their conclusion is. The classic example of that is the abortion issue. It splits every group down the middle.

**EB: Really?**

TS: Sure.

**EB: That doesn't change does it?**

TS: No, not really.

**EB: Have you seen a change over the years?**

TS: Oh, somewhat politically and legally but I don't think that there is a great change.

**EB: I mean among the fifty students?**

TS: No, it still would be split and there are a fair number who are uncomfortable since they are in medical school, acknowledging publicly their support of assisted suicide because they feel somehow that it is against what the ethic of medicine is. But they would confide to me privately that they were worried about this issue. There were these kinds of conflicts and I often said, "Well, come into the real world, many of these issues are unresolved, there isn't a clear-cut." You have to act in a way, which is acceptable to you but also acceptable to patients. The bottom line of such a conflict between patient and physician is that the physician, of course, can never abandon their patient but simply say Mr. Smith or Mrs. Smith I can not acquiesce to your wishes, I can't do what you are asking me to do and I am going to have to refer you to some other physician who might grant your wishes, but I no longer can be your physician. A physician has the right to be a conscientious objector and withdraw from the care of a patient if he/she is unable to deal with what the patient is requesting. Just as the patient has every right to fire the physician and ask for another physician because the physician will not abide by their living will for example or abide by their durable power of attorney. If the patient wants an abortion and the physician won't do it or if the patient wants a large dose of morphine or other medication in order to overdose and the physician is unwilling to participate in that kind of suicide attempt.

**EB: This could really be their first exposure, couldn't it?**

TS: On paper. Yes, unless they have had some type of ethics or philosophy course in college they might have had prior exposure. Or if they have had some personal experience, some people have had such experiences with their own family members or a loved one. Dealing with taking grandpa off of a ventilator or a sister who got pregnant and had an abortion that was disruptive to the family or a child who is born with severe birth defects and is institutionalized or a couple who wants to go through in vitro fertilization to have a baby and members of the family object on religious grounds. So, these kinds of conflicts are not just between doctor and patient. These conflicts revolve in a family and in a society. What I tried to do in the ethics curriculum, which we still do, (I teach it every year), is to confront the student early on with these issues at least as they appear on paper and in the news. Now, quite different when they get to the hospital and they have to personally deal with a patient or a family about these issue. Most of the time those revolve around when is it time, not to resuscitate, when is it time to withdraw life support and allow the patient to die. So, those are the kinds of issues. How may times do you resuscitate a patient before you finally say this is futile treatment. So, those are kinds of issues and later as we get into this further, if you want to see the actual outline, I'll give you an outline of the curriculum. We have been doing that now, (I'll look it up), but I think the first time I did that was in 1985.

**EB: I would like to include an outline of that curriculum. I don't think the average person**

**knows. We know what students get in the way of anatomy and physiology and that kind of thing but I think the medical ethics exposure is something of interest to the public.**

TS: What I did and have done ever since is when I returned from my sabbatical I then began to participate with the ethics committees of the hospitals. St. Mary's, developed under Sister Damien with my help and the VA developed an ethics committee, Washoe also developed an ethics committee. Parts of it came out of the Baby Doe conflict. When the big "Baby Doe" issue was in the national scene, Dr. Everett Koop was Surgeon General and Ronald Reagan was president. There was all this concern by the federal government that somehow babies were being killed in nurseries, which was not the case but that was the public perception. There was concern that babies were being abandoned, allowed to starve to death, etc. Well, at that time, as a part of a federal program, (actually as a law), hospitals that were getting federal dollars were expected to have ethics committees established. Particularly ethics committees for the newborn nursery. That is when I helped Sister Damien and John Brophy, (I guess he was there at the time or maybe Ken Maclean was still in that job), and a few others put together an ethics committee. This committee would help neonatologist, parents and others who were dealing with a newborn with severe disabilities or a newborn who had a lot of problems. They would act as an outside group "objective outside group" which could look at the ethical issues and decide if a particular infant should be treated or allowed to die. Frequently the physician might say continued treatment is futile and not only is it futile but it is imposing an enormous burden on this little infant. One of the parents or the grandparents would say, "I believe in miracles, let's keep treating". There would be all this kind of conflict, not unlike the conflict in adult ICU where one person would say keep grandpa on a ventilator and keep him going and maybe he will recover and others saying this is nonsense he is not going to recover. At any rate, the hospitals started to develop