

**Perspective of Change:
The story of civil rights, diversity, inclusion and
access to education at HMS and HSDM**

Interview with Harold May

Part 2 of 2 | May 11, 2015

JOAN ILACQUA: [00:00:00] Hello. This is Joan Ilacqua. Today is May 11th, 2015. I'm here doing an oral history for the Center for the History of Medicine with Dr. Harold May. This is our second oral history interview. The first took place on April 9th, 2015. Dr. May, do I have your permission to record this interview today?

HAROLD MAY: Absolutely.

ILACQUA: Wonderful. And so last time I was here we wrapped up talking about the Wrentham State School and your work there. And I was wondering if you could tell me a bit about the end of that experience and retiring in 1994.

MAY: Well, the 19 years that I spent as the director of medical services at Wrentham Developmental Center were unexpected for me. I'm a surgeon. So what am I doing in a facility for mentally retarded individuals? Well, I believe that that's the way my road was directed, because there are many insights that I was able to get there that I don't know if I could have gotten any other way. Because here in this

facility that had more than 1,000 individuals who had mental retardation at the time that I first started there in 1975, and so many of them were misunderstood by society, and they were so-called institutionalized, well, these are human beings. And I had a lot to learn during that time. We all -- I think that we all had a lot to learn. I think the most important thing that I had to learn was an approach to being able to see each of these individuals from the point of view not just of their weaknesses but also in terms of their strengths. As I say, I'm not -- I was not a specialist. And I still don't consider myself a specialist in the field of assessment and planning. But I became a part of the team. And I could see that the situation at the end of those 19 years were very different than they were when I first went. And that's because of the large group of individuals around the state who really worked together to come up with a solution to how we could better their -- improve the quality of their lives. And we did that by seeing each one of them as an individual. And each one of them had an individual support plan that was unique to that person. There was no way of saying, "Here's our service, this is the service that we provide." Well, no. The question is what supports does that particular individual need compared to some other individual. And I

think that that is a universal fact that we have to see each other as individuals. And so by the time that I was to retire on September 1st of that year, 1994, I really wasn't sure what it was that I needed to do. I knew where I had to be. I had to be in the cities where black kids were killing black kids. I didn't know the answer to their problems but I knew that that's where I had to be. Within three weeks after I retired on September 1st of that year, I saw a picture on the *Time* cover that left an indelible mark on me. It was the enigmatic face of an 11-year-old boy [00:05:00] named Robert Sandifer, his nickname was Yummy, who lived in Chicago, who had lived in Chicago. And he had been killed by fellow members of a gang called by -- of all names, they called them the Black Disciples. He had been killed by these fellow gang members two days after he had killed a girl, a 14-year-old girl. Now in the first paragraph of the -- an article that ran in *Newsweek* about the same boy, it said that a child abuse worker said something that made Robert Sandifer, that's Yummy, snap. And he swore at her and said he's going to cut her. And then it said he was less than three years old. Well, that's what did it. And that's where Wrentham comes in. Because in Wrentham the one thing that each of the individuals who were residents of that facility, the -- we

called it the Wrentham State School at the beginning, but by the end of that time we called Wrentham the Wrentham Developmental Center. The one thing that each individual had was a degree of mental retardation. The mental retardation did not define them but it described the problem that they all shared to a greater or lesser degree. But the -- it was unique for each one. And for those who were profoundly retarded it had profound effects on other organs of their body. They had gross deformities because their central nervous system wasn't working properly and that meant the musculoskeletal system, the muscles and the bones, were deformed, because they just weren't working right. And that may have had an effect on the cardiovascular system, the heart and the lungs, or the kidneys. In other words, all of the organs of the body have to work in harmony with each other. But the fact that the central nervous system was not working properly threw off other systems in a variety of ways. Well, I was sure that when I saw this paragraph, when it said that he was less than three years old, his brain wasn't developed. It was the brain, the most rapid part of the development of the brain is the first three years of life. And so that's what -- it was the environment that surrounded him that had an effect on the formation of his brain. And later on in

the article it mentioned his mother was a drug addict and his father was in prison. And so I could see it so clearly, that what we need to do as a society is to create an environment in which all babies, it doesn't matter whether they're black or white, rich, poor, what their religion is, what nationality they are, what part of the earth they're in, all babies have brains that are -- can't tell the difference between the brain of a black person and a white person or people of other nationalities. So it's so clear that all of the systems of society should be working in harmony with each other just as the systems of the body do. [00:10:00] And if we will just learn -- if we will get that understanding, if all of us will get that understanding, have that understanding, then that's the way society should operate. Now I really didn't think at that time in terms of family. What I thought of was in terms of the systems of society working in harmony with each other. But what do you do with that? What do you do with that? Well, I knew the person that I had to talk to was someone I respected greatly. And he was an authority on the development of babies and children, Dr. Berry Brazelton at Children's Hospital. He spent his life studying this and he had a center that was focusing on child development. So I knew him. He knew me. So I met with him. And he was

very gracious with me and gave me a number of articles that he had written. And in the articles he spoke about the family system. I love that word system. Here's a person who has an understanding of what the needs of society are. If we have a family system that will surround the baby with the environment, the nurturing environment in which the baby's brain can develop, so the baby can feel cared for and loved and nurtured and secure, well, that's what we need for society. Well, I had another reason that I wanted to speak with Berry Brazelton, because I knew that he knew Hillary Clinton. And I knew that she had worked with the Children's Defense Fund. She was interested in this field. And so I hoped that she might be interested in doing something with this. Another person that I thought of was Professor John Kenneth Galbraith at Harvard. He was a well known economist who had written many books including *The Affluent American* -- or *The Affluent Society*. And so I spoke with him, because I knew he knew Bill Clinton, who was the president. Now that was -- I met with him -- I met with both Dr. Brazelton and Dr. Galbraith in November of 1994. And I told Dr. Galbraith, "I wanted to be able to talk with you now because I hope you'll be able to reach President Clinton before he has to come up with the State of the Union address in January, because I hope he will

talk about this." And Dr. Galbraith is really quite a character. He's brilliant, a giant of a man, six feet six but very gentle. And he chuckled and said, "Well, the State of the Union message, that's not going to be important. What you need to do is to really work with a group and come up with a plan. And I'll be glad to work with you." He said, and I'm almost quoting word for word, "We have here next to the control of atomic weapons the [00:15:00] most important problem that society is facing." Now that was serious. But then he went on to say -- well, actually it may not have been in that conversation. I met with him on a number of occasions because he really was interested in this. He said, "I'll be glad to do anything, I'll be glad to write something about this, because I have a knack for that kind of thing." I thought that was so characteristic of him. Now as a matter of fact he did mention that -- after we'd been talking for a while, he did mention that he was working on a book about this called *The Good Society*. And actually *The Good Society* was published in 1996. And he did send me a prepublication galley of the book. But I took his advice. And there's one other person that I met. And that's Dr. Julius Richmond, who had been the surgeon general in decades past. And he too was very interested in this. So now the question is what do we do.

Well, I did send a letter to Mrs. Clinton, and I thought if I sign it with my name, she doesn't know me from Adam, but I also included Dr. Brazelton. But I got no response from her. And of course John -- Professor Galbraith had let me know that it really wasn't worthwhile to try to get to President Clinton so it would come and be part of the State of the Union address. But the question is still what can I do with this. It became clear that what needed to happen was we had to do it. We had to make sure to identify a place where there were real people and actually put this into motion, put this into action. Well, as I researched about the city, what organizations there were in the city that were already doing this, it seemed that Dorchester was pretty advanced. There was an organization there called Dorchester CARES. CARES was collaboration, see, I forgot what the A is. R was resources. E is education. And S was services. I'll think of the A. But I did make contact with that organization. Now it turns out that at the very first meeting of that organization they mentioned an organization that was sponsored by one of the social service agencies, social support agencies in the city. [00:20:00] It was called Family TIES, T-I-E-S. Together. Again the E is empowered. And S was sober. Now this organization worked with families like Yummy's. They

worked with substance-abusing families. And they were effective. They found ways. They recognized the fact that this is complicated and there are steps in working through an addiction. You may avoid it, avoid trying to do anything about it. But if you do try to do something about it, there are going to be slips. But if you get through all of these steps, in a significant number of families they are able to conquer this. And it turns out that you have to focus on all members of the family, not just the abusing one. But I thought that's it. I have to work with that. That's the organization that I can work with. I'm not an expert in this. I have to learn how you do it. Well, these people were -- had developed a true understanding by action, by actually doing it. And so I met with them. And I told them that I was ready for FAMILY to ask for funds. As a matter of fact one of the people that -- I met with a number of individuals aside from the ones I've mentioned, including Matt Fishman, who was the director of community benefits division of the Partners HealthCare. Partners HealthCare was the organization that was founded by the joining together of Peter Bent Brigham Hospital, the Robert Breck Brigham Hospital, and Boston Hospital for Women. I had been the first director of the community outreach, the community medicine, or the

community health division of the Peter Bent Brigham Hospital. Well, this Matt Fishman actually was the head of the division that sort of developed from the one that I had been the director of. And he loved this concept. He told me that he wanted to support it. Well, when I met this Family TIES group, I met with them on a Monday afternoon. And they were disheartened because they had run into -- their funding had been stripped. And they were going to be -- were going to have to disband. I said, "No, you can't disband. You're doing what's -- you're doing the right thing." I said -- I told them that I'm ready for FAMILY to get funds, but what I really want to do is make sure that you get the funds that you need, and we will work with you. I mean we have to learn. I mean you're what we consider needs to happen. Now as a matter of fact I didn't mention the word FAMILY because there wasn't -- FAMILY wasn't organized yet. Wait a minute, I'm getting -- no, as a matter of fact FAMILY was organized. But in any case, FAMILY was at the stage that it was ready to get funds.

[00:25:00] So I got in touch with Matt Fishman. And by the end of the week he called to say that the Partners HealthCare is giving \$50,000 to Family TIES program, which enabled them to continue for six months. Now there's another thing that I should mention. You see, by this time

I knew that we needed an organization. And so we had formed a small group. By that time we're into April of 1995. By April of 1995 I think I mentioned earlier that in the middle of the night the idea of FAMILY came to me. That I had attended a meeting that had been held at the Boston Foundation to support what we were doing. And something was said during that meeting that triggered my thoughts so that that night in the middle of the night I suddenly woke up with the idea. Now it's FAMILY. Fathers And Mothers Infants. And I didn't know what the L was. But that was -- Y is Youth. But a week later I was speaking to the person at the Boston Foundation who had called the meeting that I had attended, the meeting at which I got the thought of FAMILY. Just because at that meeting someone had spoken about organizations that were effective and she mentioned AARP, the Association for Retired Persons. And it was that that triggered in my mind the FAMILY, F-A-M-I-L-Y. And so when I spoke with her and said, "I don't know what the L is," she said, "How about eLders?" And I absolutely -- that's it. That's it. Now the mayor's office shortly after that or in September of that year, the mayor's office announced that funds were available for some organization to work with families citywide. And initially I thought this would be a

wonderful opportunity for FAMILY. But the leader of the
Dorchester CARES applied for the funds, calling the
organization Connecting the Dots for Boston Tots. And so I
disbanded our -- the group that was working on coming up
with a plan for FAMILY so that we could work with
Connecting the Dots, [00:30:00] which is what I did.

ILACQUA: (throat clearing) Excuse me. So I'm curious because
it sounds like at least at the beginning you were spending
a lot of time doing research into the community, learning
what other organizations were doing, working
collaboratively with them. Although you had the FAMILY
idea in the back of your mind at the same time. So my two
questions coming off of that: one is when did FAMILY
become its own entity and what spurred that? But also,
looking back, you had studied public health and you had
worked with community health before, and so it may be a
matter of being humble, but you did have an -- some
background in this, getting into it.

MAY: Oh absolutely.

ILACQUA: And it sounds like it's something that you had been
interested in for a long time. It didn't -- although there
was a catalyst in 1994. That other moments were leading
you towards this. So if you could pick up on either half
of my rambling question there. Where does the story go?

MAY: I'll be glad to because when I said that I'm not an expert, what I meant, I'm not an expert in child development. I do consider my calling public health. So I did feel that I have an understanding of issues of public health. And I do feel that I -- I knew that the key to public health is the same as the issues that I raised about the individuals at the Wrentham Developmental Center. Public health is not just some vague abstraction for the public out there. It's something that applies to every single individual who's out there. And their needs may be -- may vary. Now there are some needs in common of course. We need good drinking water for example. We need to have an understanding of diet and those various things. But in my training in public health I did get my MPH while I was at the Brigham. I did have to take a course. I shouldn't say I had to. But I did take a course in education. And I believe that that was the best course I've ever had in my life because it described how you can organize an educational presentation so that others who take that course can find it will guide them in whatever field that they're trying to make an impact. And I was thinking. I had to write a -- I had to develop a course. I think I mentioned this earlier. And the course that I did develop was a course on emergency medicine. And that was for fourth year medical students.

It was well received by the medical students. It taught them, each of the medical students, how each of them should have a way of approaching any emergency situation, whether it's for an individual or for a group of individuals. And that led to my involvement with the emergency services system for Boston. [00:35:00] So all of these things come together then. So when I spoke about not being an expert, I was really referring primarily to -- I'm not an expert in -- in the first place I wasn't an expert in mental retardation. There's a lot I had to learn. I'm not an expert in child development. There's a lot that I had to learn. And I think that that's very important though. I think that we as a society should be a learning society and we should realize that we do have a lot to learn and we -- there's a lot that we can -- we may be able to teach some things but we have to learn some other things. And they all kind of fit together. We should be teaching and learning at the same time. Learning and teaching others, so that we pass on some of the things that we've learned. Because I believe with all my heart that each of us is here to make the world a better place. And I praise the Lord for giving me the opportunities that he has given me to do that. I can't see a mess out there and not wonder well, what should I be doing here. Whether I'm an expert in that

or not, join with others who are experts. There are always going to be experts in whatever the field. Find them and work with them. So I don't know if that answers your question.

ILACQUA: Oh, it does. It definitely answers my question. Like I said, I was curious about the experts and the learning and the first steps out there into learning about at least Boston's communities and what changes you could make here. So we're in about 1995. I hope I'm not jumping too far ahead but how long was it until FAMILY was its own organization?

MAY: Well, it became an organization on September 25th, 1997.

ILACQUA: Okay.

MAY: What happened is -- I mentioned that we got the \$50,000 from Partners HealthCare that we were able to give to Family TIES organization. But unfortunately, when that money ran out they were not given additional funds by their sponsoring organization. It's so sad because it was such a good program. But their staff was still out there. They had been laid off. Well, I found Sue Parker, who was the supervisor of that program, of the Family TIES program. And I told her. She had been laid off. So I told her that I would like for her to work for FAMILY. Now FAMILY had -- the idea of FAMILY had come in April of 1995. So in

January of 1997 actually Sue Parker joined FAMILY part-time. Because we had very little money. But we were working with Connecting the Dots for Boston Tots. I mentioned that they had sent an application for the funds to the mayor's office. [00:40:00] And they were awarded funds to work with newborns. Now I knew that that's exactly where things had to start. And so my plan had been that FAMILY would start to work with newborns. But since Connecting the Dots had gotten funds I agreed that I would work with them and support what they were doing. And now Sue was available for a specific issue that had come up in Dorchester where money had been awarded to the Dorchester Neighborhood Service Center. That's a center that is part of ABCD, Action for Boston Community Development, the largest antipoverty agency in New England. Well, that ABCD had a branch in Dorchester, and that was the Dorchester Neighborhood Service Center. They had agreed that they would run a program for adolescent mothers. So in 1997, in January of 1997, Sue joined FAMILY. And it turns out that the Dorchester Neighborhood Service Center had applied for the funds and they said they'd have the program. But there was just chaos there. The director reneged on that and actually there was a time when they wondered what they were going to be doing. Well, that's when Sue was able to take

that program, at a time when the director left. So that -- now she did that as a member of FAMILY. FAMILY was not incorporated yet. That was in January of 1997. In March she joined FAMILY full-time. And then we realized that we really needed to be a 501(c)(3) organization, a nonprofit organization. So we needed to incorporate, which we did in September that year.

ILACQUA: Excellent. And so FAMILY -- I can -- I'll say becomes official in September of 1997. It had been out there. But I know that now FAMILY is involved in Boston and in Haiti. But at the beginning were you looking specifically at making change in Dorchester? Or the city as a whole? I'm curious about how FAMILY has evolved since 1997.

MAY: Right. Well, that's a good question. It became clear that it had to be real with real people. Which by definition means that it has to be individualized, so it has to start small so that -- and it has to grow. Because there are only a limited number of individuals who can get this concentrated attention. See, this brings up a very important issue, [00:45:00] because the city had a lot of programs, but these programs were funded by what we call categorical funding, which means that the funding might come from one agency for such and such a purpose and another agency, a completely different agency, for such and

such a purpose, and then a different agency for such and such a purpose, the purpose being defined by the agency. Rather than having the agency's response to be directed by the person who needs the services. It was so clear that we're doing it wrong. Instead of having the politician say, "I want this and I want this for say drug abuse," and another might say, "I want this for child abuse," and another might say, "I want it for some other related reason." But each of them looks at it with this tunnel vision, you see. A tunnel vision in which the person almost gets lost. You can't be comprehensive, you can't surround that person with all of the supports that he needs, unless you have the surrounding of everyone. See, here's where that experience at Wrentham Developmental Center was so important. Because with the individual service or support plan, the psychologist had something to say, and the educator had something to say. The medical person had something to say. Each from their point of view. Here's what's needed. But it all had to fit together into one program for that specific individual. And the Family TIES knew what that was. By the way the E in Family TIES was empowered. So we have together, empowered, and --

ILACQUA: Sober was one of them.

MAY: Sober, right.

ILACQUA: And there's an I but it'll come to us.

MAY: So anyway. Yeah. So anyway, we had this categorical funding. Now at the same time that Sue was working with these adolescent mothers I was working. I learned that there was a Fatherhood Program for the fathers. And I thought well, we need both. We need the mother and we need the fathers too. So I became involved with them, with that group. And with that group I met with John Wagner, who was the deputy chief of staff of the secretary of the Executive Office of Health and Human Services for the state, John Ford. And he was interested in this Fatherhood Program. Well, I got in touch with John Wagner and told him I would like for Sue and me to meet with him and with a senior representative of the Department of Public Health and a senior representative of the Department of Social Services to talk about this funding because -- I was mentioning about the categorical funding. I had read in the *Boston Globe* a recent article at that time that Boston had -- or the state had a \$700 million surplus. And so the proposal that I wanted to present was that the Executive Office of Health and Human Services would allocate 1% of that \$700 million for research in interdisciplinary funding for substance abuse or other issue, [00:50:00] but Family TIES

was the model. I couldn't get out of my head the fact that Family TIES had died. I thought they had it exactly right. They were doing the right thing. Well, John Wagner was very enthusiastic. He loved this idea. So we had a number of meetings and you'll die at what I'm going to say, but the afternoon came when at the end of the meeting he said, "We're ready. We're ready to go." That night I went home elated, turned on the TV, and there was an announcement that John Ford, the secretary of health and human services, was resigning. Oh.

ILACQUA: Oh.

MAY: Can you imagine? So there goes that. Well, the person who followed did not pick up on it. Which brings up an issue that I think is really very important. You asked, "Well, how do you actually do it?" Well, you do it by trial and error. You don't say, "I have a plan, my plan is I'm going to do this and then I'm going to do this and then I'm going to do this." No. That's not the way it works. Well, you have to have a plan. You have to have a plan. But in this society of ours you have to be nimble. You have to be able to see opportunities. You have to have the vision that for a system by definition a system includes everybody. If you have a health care system it doesn't include maybe 98% of the population, it includes 100% of the population.

Because one person may be having a cardiac arrest and the other person that is part of the system may just have poison ivy, but still they need to have -- be -- they need for the health care system to be structured in such a way that they can get the care that they need that's appropriate, accessible. And so if we all have that vision that we have to develop the systems, the health care system, that meets the needs of all of the individuals, the education system has to include 100% of the children. And their needs may be different, but there's enough grouping so that there can be wonderful programs, but there's no one person who can do it all. You see, the key to it is to find a way to group ourselves together to say, "Here's what we are going to do." So it's not here's what I'm going to -- here's what we are going to do. And we're going to -- in other words you have to connect. Connection with others is vital. And the model for this has always been the baby's brain. Now that started in 1994. Now I don't remember the dates, but in 1995, '96, '97, '98, along in there, there were *Time* covers. The baby's brain. People started to realize [00:55:00] that it's important to realize that the baby's brain -- that an understanding of the development of the baby's brain is vital for any society. That means that you will have early intervention,

realizing that most of the development is early. The earlier you can intervene in the life of a child, the more effective that intervention is going to be. So those are some of the lessons then. You were asking about the development of FAMILY and how did it work, it was in Boston and then in Haiti. Well, through -- you have to find like-minded people. Like Sue Parker for example, Family TIES, that organization. It would be a crime, you see, if that organization were just disbanded and then those -- the people who had staffed that individual -- that -- if they had just left to some other job. Well, that whole way of doing things could be lost. It's vital, you see, that some people hold on to that. Whatever is a good way to do a thing, don't let that die. Make sure that somebody or some of us join to make that happen. So with FAMILY often these are just chance encounters if you just meet someone and they ask, "Well, what are you doing?," and oh, you're doing that, well, you must talk to so-and-so. I think that's the way it happens. It just happens by -- listen. All we have to do is listen. And ask ourselves, "Should I be doing something about this or can I do something about this?" And it turns out that it's exciting. It's an adventure of discovery. If you're willing to say -- the one ingredient that's necessary though is we have to say -- we have to be

talking with other people who say, "I want to do something about this but I don't know quite what to do." Find those people. And then together we'll be able to help each other. But the FAMILY approach is really -- it's very simple. And it turns out to be universal. One thing for me was it was clear that this had to start at the beginning. You had to start with -- even before the newborn. You can't start with the newborn. You have to start with the pregnant woman, even before she becomes pregnant, and the father. But given the fact that the brain development is -- we talk about nature and nurture. The nature part. Make sure you understand the nature part. This is the way the baby's brain develops. Well, the nurture part says since that's the way the brain develops, here's what we have to do. We have to make sure we start at the beginning. Unfortunately, with us, [01:00:00] we weren't able always to start at the beginning. Now with Sue Parker and the Dorchester Neighborhood Service Center in January 1997 when she started to work with those adolescent mothers, I was hoping well, that's the beginning then. Because we are talking about adolescent mothers. We're talking about the babies. We can start there. Let that be -- if we'll work with them, then find out well, what do -- how many are there, what do we need for this one

and this one and this one. Unfortunately for that money became a problem. We had but so much money. It became clear that we needed -- the high priority for us had to be to get the money to pay Sue Parker. Then Alice Gomes, who was a partner of hers who had been working with Family TIES, was available. So we hoped that she would be able to join us. We were able to get her to join us. And so Sue and Alice were working together at the Dorchester Neighborhood Service Center. And they could form a stabilizing influence. Remember now the Dorchester Neighborhood Service Center at that particular time was in chaos. The director left. Well, that director was followed by Leonard Lee, who came in to be the director. And he was a whirlwind. He was incredible. So Alice and - - I mean Sue Parker and Alice were able to have that program for adolescent mothers -- [01:02:06]

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MAY: [00:00:00] -- in that Neighborhood Service Center with the new director. And I hoped that that would be -- we would be able to start there. But as I say, it was a matter of money. I want to point out something though. That as we were at the Neighborhood Service Center, we just looked

across the street, and that is the Lucy Stone School. So in the back of my mind I knew well, at some point we're going to have to make a connection with the Lucy Stone School. Because that's part of the education system. And then we had heard about the Codman Square Health Center, which was down a few blocks away, so we got in touch with Bill Walczak because we knew that we would have to connect with them.

ILACQUA: So I feel like it's important to mention on the recording that as you talk about this everything is sort of circles within circles connecting and branching out from there, and working on a very almost one by one individual basis to get this growing and to get it out there. And so as FAMILY has grown and as FAMILY has gone on to work collaboratively -- excuse me, collaboratively in Dorchester, what sort of changes did you see? Or rather, did you see changes occurring in the community? Did you see -- did you start working with community members in Dorchester? Because you've talked a lot about these key players, about Sue, and about people who were movers and shakers on the providing service end of things, but not too much about the people that you're working with. When did that start to happen?

MAY: Well, remember, you see, at the same time we were working at the Dorchester Neighborhood service Center, I was still working with Connecting the Dots for Boston Tots, because they did have funds. They were working with newborns. Now their concept though was different than mine, than FAMILY's concept. They felt they would have a limited amount of money, so that they would be involved only for three years. And they would do certain services. So they'd visit every newborn, every mother, and give -- have a welcome baby basket that they would present. It was good but it wasn't the comprehensive supports that I felt was needed. But part of that group was Maryanne Kirkbride, who was the director of community health for the Codman Square Health Center. And Elisa Bland was -- worked for Tufts University. They had a program for newborns in the Codman Square Health Center. It was called Parent-to-Parent. So I was -- I could see that we have to make connection with -- we had to make connection with Codman Square Health Center. We can't do this without being there with the Codman Square Health Center because that's where the babies are. The babies are born in a hospital. They're not born at the Codman Square Health Center. But the mothers come back to the Codman Square Health Center. You can't have FAMILY [00:05:00] as an organization without having the

Codman Square Health Center say that we're members of FAMILY, here's what we do, and this is the way we do it, for all of our babies. Well, but they did have a program called Parent-to-Parent. In the same way that I think Family TIES had the right idea, well, Parent-to-Parent had the right idea also. It's not as if that was the only one. See, there are a lot of programs. And some of them are really quite good. But all of them are limited. Well, FAMILY is limited. But the difference between FAMILY and them is that FAMILY's plain mission -- prime mission is to connect these programs, and where necessary they have to be the one that connects with the individual. The whole idea though is you have to connect with the individual. Certain programs may connect with some individuals. Others connect with others and others. But FAMILY is the glue that connects them all with the individual. And the individual is as much a member of FAMILY as the program support person is. They're all members of FAMILY. Now Maryanne Kirkbride and Elisa Bland and the director of women's health for the Codman Square Health Center worked together to -- so that we could present a proposal to the Codman Square Health Center that FAMILY would start there. Now Bill Walczak was very interested in FAMILY and scheduled a meeting of our group with the staff in early 2000. Unfortunately the

staff -- one member of the staff in particular -- felt that -- she felt that they should organize a little bit further before they start, not realizing that FAMILY is itself an organizing system. You don't have to organize in order for FAMILY to start FAMILY. And that's an organizing system in itself. If we would only focus on the needs of the individual person, the individual child and family, that's the way we organize. We're responsive to that. So it became clear that we shouldn't give up on the Codman Square Health Center but they weren't -- they just weren't ready. But in 2000 -- the year 2000 it -- we were told that funds were available to start a program in the schools. So with that in mind, remember I mentioned that when we were at the Dorchester Neighborhood Service Center we looked across the street and saw the Lucy Stone School. Well, we did talk. I did talk to the principal of the school, and she was thrilled. I talked with her in May of 2000 offering to bring FAMILY to the school. That was a second choice. You see, we would have preferred to start FAMILY at the Codman Square Health Center with the babies. [00:10:00] Because we're missing -- see, we're missing all of these preschoolers, the babies and the preschoolers. And we'd have to take the kindergartner who come to Codman Square Health -- or to the school who do not have the benefit of

the supports that they need. But we did that because it's the only option that we had. And here again there was just a chance meeting with someone who said, "Oh, this is a wonderful idea. Oh, you must talk to Pam Bailey. Pam Bailey is just the person that you need. She's a family educator, she would be just wonderful for this position of family advocate. And you must talk with [Amy Huff?], who is a fundraiser." Because we were having problems with fundraising. We didn't -- I'm a very poor fundraiser. And by that time we had a very loyal and very good board of directors of FAMILY, but I was not strict at all in asking them to make sure that they played their role in fundraising, so that unfortunately fundraising has been -- was an issue for us. And that as I say, the decision was made to start that program with -- in October of 2000 with Pam Bailey working with 25 -- the 25 children in the kindergarten class. So let me see how I'm doing with your questions.

ILACQUA: Oh, we're doing fine. I wanted to make a comment.

The fundraising takes a certain type of person to stay on top of that. And it's always hard to get support for just about anything. But it's especially hard when you're very committed to an idea and the funds are not always there for you to be able to go out and do exactly what you want. But

it sounds like over time FAMILY has adjusted to be able to at least be out there in the community in ways that it could be, even if they weren't the ideal list of plans in motion that you would have wanted.

MAY: Exactly. Exactly.

ILACQUA: So between '94 and 2000 FAMILY went from an idea to a project to a program. And the way of describing it as a glue was very helpful, because I have my notes going here. And I was going all right, you're working with mothers here and fathers there. And so it makes sense that it's there making connections. I'm still curious where Haiti comes into this though. Because you're in -- I might be jumping years ahead.

MAY: No, that's OK, no, that's OK.

ILACQUA: But you're in Boston, you're making connections, and you're working this program into the community. And then we're jumping south and in a way almost jumping back in time, because you were in Haiti in the '60s I believe.

MAY: Right.

ILACQUA: So what brought you back to that? What brought you back there? And what brought FAMILY there?

MAY: Well, what happened is in 2008 I just felt look, I'm getting on in years now. And I want -- I still want to make sure that FAMILY comes -- that Tuskegee comes to

Haiti. You see, when I was in Haiti I had no idea about the FAMILY concept. [00:15:00] What I had in mind was the Tuskegee concept. Because that's what I knew. Tuskegee after the days of slavery was the center for development for the South, for the rural South, along with a number of other college -- well, they were institutes or educational facilities for former slaves. And I knew that it worked. I knew that that was the key to development. They worked together so that together they were able to develop the whole community sustainably. And I knew that that's exactly what Haiti needs. And so we had started the Ecole La Providence, the elementary school for 75 children, in 1962, and each year another class had been added. But then when I learned that Dr. Mellon, the founder of the hospital, said that the school would not be able to go beyond the primary level at Deschapelles where the hospital was, we moved it to the nearby town Verrettes. And we had maintained our interest in that school throughout all of these years. But in 2008 it was clear I just had an inner urge that I had to go back to Haiti to make sure that we bring this concept. And by that time it was richer. It wasn't just Tuskegee. It was FAMILY. What I knew was that FAMILY is global. It's not limited geographically. It applies everywhere. And so in March of 2000 I went along

with a group from upstate New York. That group from upstate New York had been going to Haiti, and they were supporting children from -- graduates from the school or children in the school following Josephine Ernstein, who had been a teacher who we had met in a trip to Ithaca to Cornell in 1968. She had retired as the French -- the head of the department -- the French department at Ithaca High School. And she was interested in doing something in her retirement. So she had come down to be with us in 1968 and '69 and the first part of '70. We left in 1970. But she continued. And through her this group in Ithaca had taken an interest in the school. And so I went with them for a 14-day trip. And I brought with me the copy of the FAMILY worldview. We didn't call it the global positioning system at that time. But it was the forerunner of the FAMILY -- the global positioning system that you have seen. And the people there who I met with, most of them were -- or some of them were [00:20:00] relating to the school but others were special development people from in the community, including the mayor. And they were all very very interested. So they said, "Yes, we want this." So that was in March of 1968. In August of 1968 I met a Haitian lawyer, Pierre Noel, who it turns out had taken a three-month course in international development. He had been

born in Verrettes and he wanted to go back to Haiti to work in development. I met him and it just seemed that he is exactly the right one to go back to Haiti, if he would be -- and he loved the idea. I said, "We don't have money." But he said, "That's all right, I'll try to get funds." So he and his wife went in 2009 and for -- in June -- I mean in January of 2009. And he did -- he got a team together. The Verrettes commune is 137 square miles right in the center of Haiti. The Artibonite River runs through it, or it borders, it's the northern border. And the rice belt, the most productive land for rice in the country, is right there. But then they have two-thirds of the land is in the valley but then one-third is in the mountains. And the people, especially in the mountains, are very very poor. But Pierre assembled a team, which is still there. And they did surveys of schools. Something that pleased me very much is that they spent quite a lot of time in the mountains where many of the children did not have access to schools. And they developed the plan for a teaching institute -- teachers' institute. And they're there now. Now Pierre, here again we did have a problem in getting all the funds that we would need. But of all things, something remarkable happened. Remember he got there in January of 2009. In January of 2010 was the earthquake. And all of

the eyes around the world turned to Haiti to -- people wondering what they could do to help. Now it's providential of course that he was there and that FAMILY had already started. So they were able to -- they were spared earthquake damage. The earthquake damage was south. It was near the capital city and further south. But two years -- let's see. The Haiti Fund was started by the Boston Foundation. [00:25:00] The Haiti Fund was supposed to last five years from January of 2000 to January of 2015. And guess who was selected to be the head, the director, of the Haiti Fund in Boston? Pierre Noel. So it was providential that he was able to go to Haiti before the earthquake. He had a sense of really what the needs are and so he is still now in Boston. So we're hoping that the Haiti Fund is complete now, we're hoping that he's going to be able to go back to Haiti next year. And we're going to be working with them to see how the vision for FAMILY can be expanded. See, look at all the contacts that he's made. So that I believe God is at work here. I pray that this work will move. I mean it has to. But see, these are things that we can't just plan in meeting rooms and say, "Well, we're going to do this, then that." But let's just hope it's where I'm expecting, I'm hoping.

ILACQUA: Wonderful. I have two more questions for you, I think, unless we determine that I skipped something that we should go back to. But I'd like to talk about the Global Positioning System now, the document you have written up on FAMILY, and what you hope that that will do on a larger scale. And then my last question ties into that, would be the legacy question, what do you hope happens, what do you hope people will remember? Both your work with -- or rather not solely your work with FAMILY but your work over your whole career. What people will get from that and understand about you and your life and your experience.

MAY: Could I add one other thing? I'll be glad to do that.

ILACQUA: Oh, sure.

MAY: Could I add one other thing? And that is about ProImmune. ProImmune is a compound that was discovered by a very good friend of mine. But it plays a very significant role in the present and future of FAMILY. So I think it's really important to bring it up now. I was the best man at the wedding of Dr. Albert Crum and Rosa his wife in 1956 when I was in Boston, having had my first transplant. I had been blind for a period of time until I had gotten the transplant the day before Easter that year. Now Albert Crum was a medical student while I was a resident at Mass General Hospital at the time. He and I had met earlier.

And we really felt a kinship, so much so that I was the best man at his wedding. There were only four of us at the wedding. But we kept up with each other after that. Then in 2009 [00:30:00] I decided I needed to know what he's doing. So I got in touch with him. And it turns out that he had discovered -- made a remarkable discovery. It turns out that glutathione is one of the most significant compounds in our body. It is what's called the master antioxidant. It's the regulator of the immune system of the body. It's found in every cell of our bodies. Every aerobic cell of our bodies. Any cell that needs oxygen. Any cell that needs oxygen, for any of those cells, the oxygen becomes a toxic by-product after it has metabolized. And if it is -- if the toxic by-product is not discarded, the cell will die. Well, it's glutathione that is the prime antioxidant. And it's found in all parts of the cell so that it turns out that it -- I'm sure that the -- there are so many medical conditions that are associated with a low glutathione level, a low activity of the immune system. Well, ProImmune turns out to be by far the most physiologic way to raise the glutathione level of the cell. And he is a brilliant -- he's a retired psychiatrist, of all things. But he's also a brilliant scientist. And he had discovered this and patented it. So it turns out that when I learned

about that I could see that its role in the body is very much akin to my -- the way I envisioned FAMILY working in society. And now there's a scientific understanding of this. The -- I mentioned about the brain development. Now you asked about the FAMILY global positioning system. I want to tie my answer to that question in with what we're talking about with ProImmune. Now the -- let's put the ProImmune story aside for the moment and we'll come back to it and we'll come first to the answer to your question about this, the global positioning system. It's a biological fact that we are members of the human family. There's no one on earth who can refute that. We're just members of the human family. But I think we haven't learned what the significance of that is. I think that, you see, we have made so many advances, but in our understanding of ourselves, in our understanding of mankind and our relationships to each other, I think we're in the dark ages. I think, you see, [00:35:00] this is a very sad time when we contemplate that America, which has stood to - - as a model around the world for liberty, justice, freedom. I think when we look at how dysfunctional we have been in so many ways, we're part of the problem instead of part of the solution. What is the answer? In almost any direction that we look we see wonderful things. We see

wonderful things. There have been wonderful advances. But if you look at that statement of Arnold Toynbee that mankind is going to -- we're going to kill each other unless we find some way of realizing that we're one family -- I believe that that is fundamental to our survival. If we continue to think of the other, we're us and the other is out there, we have to find a way of defeating them, and defeating that. But unfortunately, see, they're out there because they look at us and they see that we're dysfunctional and they say, "Well." When we see Ferguson, now we see Baltimore, and we -- the unrest in other parts of the world can come back to bite us, you see. We're not a fortress that can use hard power to have our way around the world. I think that we've lost our moral authority. I believe we have lost our moral authority. And we have to regain that. And when I say we I'm not being chauvinistic. I love America. I love America and I praise God that I was born here. That's a blessing. But I think the light has to start shining here. There has to be a light. There has to be a beacon that says, "Look, this is the way." And this is the way, the fact is we're one family. And here's the way to -- for us to stop our tunnel vision. The tunnel vision being when we think about them out there, the problem is out there with them. What do you mean it's out

there with them? What -- how about us? Well, what do we actually do? When we look at some issue such as the poverty, the violence, the disparity of income that is rising like this, Warren Buffett I think has the right idea. I mean I don't begrudge anyone from having -- being a billionaire. I think that's fine. But with privilege comes responsibility. And I think for all of us we have to ask ourselves the question what do I need to do to help restore our -- not just our country but just our civilization. You see, there -- during my life I've gone through the [00:40:00] Depression and World War II, the -- all of the things that have been part of our experience. But what we're -- the period that we're in now is one in which I think the answer to it is very simple, it's actually very simple. Let's take Baltimore. My hope is that if we can have one sentence that everyone takes seriously, always act as though we're all members of one family, because we are. Just that. Just those specific words, always act as though we are all members of one family, dash, because we are. We are. And if we -- now we won't succeed in doing that. But that should be our aim. Could somebody tell me, "No, I don't agree with that"? I challenge anyone to tell me that. Well, if they don't agree with it, then let's do it, let's act that way. Well,

FAMILY is the way for us to put those words into action. And it takes action verbs. Mobilize. When I was 15 -- I think I mentioned this before. The bombs dropped on Pearl Harbor. I knew that we were going to be mobilized. I was going to be mobilized just like all of the other boys. We have to mobilize the youth to a cause that's wonderful. It's not a cause that they say, "Oh, do I have to do this?," or -- no. This is a cause -- in World War II all of us boys were mobilized. And we knew that some of us were going to die. It's -- in other words there's some causes out there outside of us that are really important. And the world is going to suffer if we don't act our part. If we get preoccupied with just thinking about me, me, me, me, and what I want, I want this, I want that, and I want this. Well, what do you mean? I don't begrudge anybody anything, you see. But I think that if we recognize that we -- what we do matters, I believe that this is the simplest way that I know. This one page. This specific page. The declaration of interdependence. The FAMILY global positioning system. I believe that this is an eternal truth, that we are interdependent. We're not independent. So for anybody who says, "I'm independent and I need to do this and I can do this and I can do -- and I need to be free to do," what do you mean you need to be

free to do this? Sure, maybe yes, maybe no. There are some other people who need to be considered. So the world has great religions. And we -- people in the world either are members of one religion or they are atheists or agnostics, whatever they are, whatever their religious belief system is. Here's something that they can all have in common -- we can all have in common. And I think especially those who are -- who claim to be religious. If I'm a Christian for example it's a test for me to know well, how do I treat people of other religions. Do I treat them as just somebody I have to evangelize? [00:45:00] Or somebody that I have to love and be -- and help and be -- consider my brother? Because he's my brother or my sister. We are that. Even the terrorists. Because some of them are that because they feel nobody cares and if nobody cares about them, well, then they're going to -- their life means nothing. Well, I think when they all realize wait a minute, we're all in this together, and this is -- it's -- the greatest blessing of my life was to be born here in America. And be born of the parents that I was born by. So my hope is that someday this document will be used. And there's another thing about it. It's a living document. Some of the words have been changed as recently as a week ago. So I don't consider it perfect, and I would

personally welcome anybody who says, "I think we could shorten this sentence here or we could -- I think we ought to change this or that." I would welcome people to work on it until we all say, "Yes, this is it. And now we're going to sign, 'I believe this.'" In the same way that our forefathers signed the Declaration of Independence we should sign the declaration of interdependence. It's that -- it's just that important. Now that's the legacy too. And getting back to ProImmune, I believe that that fits in with this, with -- ProImmune can now be used as a diet supplement and a food additive. Now my hope is that Dr. Crum and I -- him and his team and FAMILY will be working together so that FAMILY will be the way that ProImmune -- the ProImmune Company will be presenting ProImmune for its medical uses. I think either ProImmune -- you see, ProImmune can currently be used as a pharmaceutical -- as a diet supplement or a food additive. But it can't be used as a pharmaceutical agent until the clinical trials have been done that will prove its efficacy in the treatment of any of -- I believe there'll be scores and scores of medical conditions for which it'll be effective. This will be long after I've gone I believe. But rather than for ProImmune to be taken over by a pharmaceutical company that'll profiteer from it, driving up the price because

it's effective in the treatment of whatever the disease might be, its expense should not be increased just because it's effective in the treatment of whatever the condition might be. But I believe that FAMILY and ProImmune will belong together, and the legacy of ProImmune and FAMILY will be inextricably linked.

ILACQUA: And I jotted this down while you were talking about the declaration of interdependence. But you've really lived a life of service in a lot of ways, of healing people and teaching people, and working for the benefit of other people and for the benefit of society, but really doing work beyond yourself. And so after hearing your story, after these two interviews, and reading this document, I can see how [00:50:00] many of these stages and steps have lined up to this point now. And I think that's really a wonderful thing. And I think that today you've answered all of my questions by this point. And you've really gone over the whole story. And so I'd like to give you an opportunity now. If there's anything else that I didn't bring up that you think that we skipped or you think that should be on the recording, now would be the time to put it in there. Is there anything else that you'd like to say?

MAY: Well, I do appreciate this opportunity that you have given. And I believe that it is in keeping with some of the things

that I've been talking about. This oral history is really very important. It's almost akin to what we were saying about Family TIES. It would have been a sin to let Family TIES, a program that really was effective in the support of families in which substance abuse was an issue, it would be a sin to allow that just to die because it doesn't have money. How can we let that happen? Well, I'm sure that there are so many men and women who have just a history and experience that is very rich, and the world needs. And you've given that opportunity. I think that this is wonderful and it's important. And one more thing. I see it as just as much history going forward as history going back. I think that what I would want would be people to become engaged, and for them to say -- I want people -- I want this to help to mobilize people, I want people to say, "Yes, yes, here I am."

ILACQUA: And that's part of it too. When we do an oral history interview and we save it in perpetuity, you never know what someone is going to get out of it at any point in the future. But I feel that especially in this interview the underlying messages of what you've done are inspirational. And I certainly think it's maybe not a safe bet, but a close to safe bet, that someone listening to this will be inspired by everything that you've done and everything that

you've accomplished. And on that note I want to thank you very deeply for allowing me to come out here and speak to you on both of these occasions and to record this interview for the Center for the History of Medicine.

MAY: Thank you. The pleasure has been mine. Thank you.

ILACQUA: Wonderful. I'm going to turn it off. [00:53:41]

END OF AUDIO FILE