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6-14-1984

## Interview with Dora Jones

Dora Jones

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**LOUISE PETTUS ARCHIVES AND SPECIAL COLLECTIONS  
ORAL HISTORY PROJECT**

**Interview #327  
JONES, Dora**

**JONES, Dora**

Columbia Area Mental Health Center employee, former DHEC employee in sickle cell program

*Interviewed:* June 14, 1984

*Interviewer:* Michael Cooke

*Index by:* Alyssa Jones

*Length:* 30 minutes, 8 seconds

**Abstract:** In her June 1984 interview with Michael Cooke, Dora Jones detailed her work with DHEC's sickle cell program. Jones discussed the misconceptions of sickle cell within South Carolina communities, the role of community groups, and what DHEC's work with these groups. Jones also discussed the merging of DHEC's sickle cell program with the Crippled Children's division of DHEC and the controversies of that merge. This interview was conducted for inclusion into the Louise Pettus Archives and Special Collections Oral History Program.

**Keywords:** Sickle cell anemia, Department of Health and Environmental Control (DHEC), sickle cell trait, Crippled Children's Division

**Interview Session (June 14, 1984): Digital File**

**Time      Keywords**

00:00:00 *Start of Interview*/Interviewer's Introduction

00:00:24 *Question:* Can you give a brief biographical sketch of your life? *Answer:* DJ was born in Bishopville, South Carolina, but moved to Columbia when she was young. She was 33 years-old at the time of the interview. DJ received her undergraduate degree from the University of South Carolina and a Master's degree from the University of Virginia.

00:01:28 *Question:* When did you first start working for the Department of Health and Environmental Control? *Answer:* Right after graduating from graduate school in 1974. DJ worked at DHEC for about three years and half of that time was spent working with the sickle cell program.

00:01:53 *Question:* Could you tell us something about the early years of the sickle cell program outside of Columbia? What was your role working at DHEC? *Answer:* Her first year was spent organizing within the sickle cell program.

- 00:02:45 *Question:* How long did it take you to develop the policy? *Answer:* About a year. After that, DJ primarily worked with educational programs for sickle cell anemia. She also helped with counseling.
- 00:03:25 *Question:* Did you find that the public was very educated about sickle cell? *Answer:* DJ found that the public did not have much knowledge about sickle cell anemia. Most had heard of it.
- 00:03:56 *Question:* What type of myths did you discover that they had? *Answer:* Many were confused about sickle cell trait and sickle cell anemia-they thought the two were the same.
- 00:04:29 *Question:* What type of people were having a problem making the distinction between sickle cell trait and sickle cell anemia? *Answer:* DJ mostly had contact with people from the local health department, so mostly the lower working class.
- 00:05:09 *Question:* Did you find any problems among the professional class? *Answer:* The professionals knew there was a difference between sickle cell trait and anemia.
- 00:05:50 *Question:* Was the fact that you did a study on sickle cell in your college career, was that a decisive factor for you being hired? *Answer:* DJ thought that it played a major role because she was connected with people in the field.
- 00:06:15 *Question:* They were looking for people with some experience when starting the sickle cell program. *Answer:* Yes, if they could find someone.
- 00:06:24 *Question:* Did the majority of people they hired have some expertise? *Answer:* DJ thought they were hired because they were intelligent, educated people that they thought would be competent.
- 00:07:20 *Question:* How many people had the expertise and knowledge of sickle cell at the time? *Answer:* A few in the Columbia area.
- 00:07:47 *Question:* Did you go outside the area? *Answer:* Sometimes, to help organize and educate in various counties.
- 00:08:05 *Question:* Did you have a certain district to work in? *Answer:* No, the program went wherever it was requested.
- 00:08:57 *Question:* Did you offer your services? *Answer:* Yes.
- 00:09:50 *Question:* What groups did you work with that you can recall? *Answer:* DJ worked with a group in Spartanburg, a group in Chester County, and a group in Gaffney.

- 00:10:10 *Question:* Can you relate those experiences? *Answer:* She found all three groups were very interested in learning about sickle cell anemia and sickle cell trait. They wanted to make their communities more aware of the disorder.
- 00:10:58 *Question:* Did you see or perceive any degrees of sophistication in these groups? Were some more knowledgeable or have different priorities? *Answer:* DJ thought that they had primarily the same goals. Some groups had more knowledgeable and charismatic leaders.
- 00:12:09 **[audio unclear]** The Spartanburg group's leader was charismatic, knowledgeable, and got things accomplished quickly.
- 00:13:12 *Question:* You mentioned politics, how did he specifically use politics? *Answer:* DJ said that the Spartanburg leader made use of his political connections.
- 00:13:39 *Question:* Did they have any influence on the state legislature? *Answer:* DJ was not sure, but they were involved with the state legislature, especially the dynamic, politically active leaders.
- 00:14:20 *Question:* Give us an example of how she was such a dynamic leader? *Answer:* She would do anything, contact people, organize meetings, do whatever was needed, and had a lot of energy. DJ said she had a likeable personality.
- 00:15:09 *Question:* Were there any other leaders in the Chester County who were supportive, active, and dynamic? *Answer:* DJ said that the leader had her own staff, but DJ primarily worked with the leader.
- 00:15:52 *Question:* Were there a good number of people who suffered from sickle cell anemia in the Chester area? *Answer:* DJ did not remember specifics, but no more than whatever the average was.
- 00:16:17 *Question:* Were members of the Chester sickle cell organization active sickle cell anemia sufferers? *Answer:* DJ was unsure.
- 00:16:31 *Question:* What about the Gaffney community? *Answer:* DJ did not have much contact with the Gaffney community other than the educational programs.
- 00:17:00 *Question:* What about the Gaffney group? *Answer:* DJ could not recall.
- 00:17:19 *Question:* What do you think about the relationship between the community groups and DHEC? *Answer:* DJ thought that the communities and DHEC had a good relationship.

- 00:18:10 *Question:* Was DHEC superior or was the partnership equal? *Answer:* DJ thought it was an equal partnership.
- 00:19:45 *Question:* Was there a conflict of authority because of the priorities set by the various chapters and DHEC? *Answer:* No.
- 00:21:19 *Question:* What role did they want DHEC to take? *Answer:* DJ did not know what roles the community groups wanted DHEC to assume. The community groups thought they could do what DHEC was doing.
- 00:22:56 *Question:* The decision of DHEC to place the sickle cell program into the Crippled Children's program. Did you think that was a fair and equitable decision? Did you think it was warranted? *Answer:* DJ did not agree that the two programs should be combined because there was much left to do in education, screening, and counseling. DJ thought that the sickle cell program would be lost in such a large program.
- 00:24:12 *Question:* In your opinion, did that happen? *Answer:* Yes.
- 00:25:27 *Question:* Why do you think that happened? *Answer:* DJ and the other staff were told that the sickle cell program belonged in the Crippled Children's program because it dealt with mostly children with the disease.
- 00:26:13 *Question:* How do you genetic counsel to children? *Answer:* You don't. You counsel the parents.
- 00:26:22 *Question:* How effective is genetic counseling to the parents? *Answer:* It's only helpful to parents in the terms of future children. That was the rationale that they were given at the time of the merge.
- 00:27:16 *Question:* What is your thought? *Answer:* DJ never quite understood why that decision was made.
- 00:27:35 *Question:* Did you have a different perspective than what was offered for consumption? *Answer:* Yes.
- 00:27:53 *Question:* Can you share the real rationale? What is your analysis of why the department changed its position on sickle cell and abolished the sickle cell program and placed it in the Crippled Children's division? *Answer:* DJ thought that the primary reason was a change in the political climate. Sickle cell trait and anemia no longer became a priority at the state or national levels.
- 00:30:08 *End of interview*