

Independent Study/ The Labor of Care Archive

Naomi Zauderer

Interviewed by
Dolores Urena

November 5, 2018
CWE, City College, NY

Narrator

Naomi Zauderer (51) has served as the Associate Executive Director of the Professional Staff Congress/CUNY since 2008. She grew up in Columbus, Ohio and Newport News, VA.

Her mother Eva Struve (84) worked as a counseling psychologist for the Veterans Administration for over thirty years.

Interviewer

Dolores Urena (43) is a graduate student at City College (CUNY) enrolled in an independent study about the Labor of Care in America with Professor Kathlene McDonald.

Restrictions/ Consent

Signed: The Labor of Care Archive Informed Consent Form

Signed: Labor of Care Archive Oral History Interview Release Form

Format

Interview recorded on November 5, 2018 in Wav format using a Tascam DR-05. One file
35 Minutes 43 seconds

Transcript

Transcribed for clarity by Dolores Urena, waiting for Naomi Zauderer to review and approve.

Naomi: Hello, I am Naomi Zauderer and I have a mother who has been diagnosed with Alzheimer's.

Dolores: and what is the care situation?

Naomi: so, she is currently in assisted living, um, at Five-Star Senior Residence in Yonkers. I am actually moving her to Memory Care at the Belvedere in Brooklyn. Um, a week from today. Monday, the 12th.

Dolores: why did you decide to do that?

Naomi: um, well, she needs to (hesitation) she needs and is actually the third time I am moving her in 19 months. (Her voice cracks) Her dementia has been progressing really rapidly and so when I first was able to persuade her to independent living at the five-stars in March of 2017 and then w, um, her doctor quickly advised that she should really be in assisting living it took a while for a space to become available but I ultimately was able to I think it was in May, yeah, 2018 I was able to move her into assisted living um, but the staff. She is (hesitation to find her words) the staff there is, she getting very well cared for, the staff do experience frustration with the dementia and she really needs to be in an environment where there is more of an effort to get the patient to socialize with each and to keep them mentally stimulated um, I visited the Belvedere twice, once alone and once with my mother and my husband and even though it is not as attractive from the outside, I really was impressed, particularly with the coordinator who has been there for about 30 years and has a real dedication and commitment to the work in general has such *joie de vivre* and really inspires confidence.(her demeanor and voice seems very hopeful as she speaks these words)It is a calling for her; it seems like the work is really a calling for her not just a job so, um...(a weak laughter) on the other hand just before coming here (interview takes place at CWE conference room)I was actually looking at Department of Health inspection reports and discovered like 25 violations over the past two and half years.

Dolores: oh no (a concern laughter in unison with Naomi)

Naomi: (nervous laughter) so, then I am like I look at where she is now and there were 14 violations, I suspect that most places are getting cited for violations, but it is a little disconcerting (more laughter between Dolores and Naomi)

Dolores: where do you live may I ask?

Naomi: I live in Manhattan in Chelsea

Dolores: and when she was in Yonkers now that she is in Yonkers, how often do you go and visit her?

Naomi: I usually see her once a week and my husband who is a nurse usually gets off work much earlier and he often tries to go, um sometime during the week. Between the two of us, we try to see her twice a week

Dolores: how old is she now?

Naomi: she is 84, she will be 85 in April

Dolores: and how advanced is her Dementia?

Naomi:(hesitates) um, is she is in a moderate stage i think she is very (hesitation) disoriented as to place that's the, um, she (pauses) for instance she when we saw her yesterday my husband got there first and she went to the bathroom and forgot he was

there changing his clothes and left the apartment and went out to a common area and she has trouble finding the bathroom in her own apartment and yeah, there is extreme disorientation as to space but she still remembers who we are and who she is, but the memory is very poor. She doesn't remember her own birthday or how old she is or her address, um, even sometimes she has trouble spelling her name, yeah (Voice saddened when relating her mother's condition)

Dolores: before she moved into an institution of a sort, did she have her own house her own apartment somewhere?

Naomi: she was in independent living in Guilford, Connecticut for a couple years, I don't even know if it was a couple of years I think it was a couple of years, um and then before that she was briefly in this condominium that she bought after her husband died. She had been his caretaker for many years, for about 12 years. He ultimately died of breast cancer um, so she has done a lot of moving in the past 5 to 7 years.

Dolores: roughly, how long ago did you realize that something not there?

Naomi: um, I realized it when actually when Fred was still alive and we went to visit and they. She was his caretaker but they couldn't find alcohol and cotton swabs to give him an injection. My husband and I went there to cook dinner and there was, it was clear that there wasn't much cooking going on; there was I mean we couldn't even, there was no salt and pepper in the kitchen um, and she (long pause) they, one of the times that he was discharged from the hospital they send him home without there was no she had no assistance to take care of him so she was having to call 911 to help him get off the toilet because she couldn't lift him, um, yeah

Dolores: aside from you and your husband is there another family member that is involved

Naomi: I have two sisters, but (hesitation) um, one of them lives in Kentucky and the other one is in California, so, they are supportive from a distance and come to visit, but not the...

Dolores: like every 6 months type of visit? or...

Naomi: yeah, two or three times a year, yeah

Dolores: Are you your mother's primary caretaker because of distance or because you are closer to your mom relationship wise?

Naomi: (pauses) I think it is primarily because of proximity, um, we (hesitation) my older sister actually very much wanted her to move to San Diego, um, and even researched places. We took her out there for 80th birthday and Andrea had arranged for us to visit several communities and we actually visited a very lovely CCRC (**Continuing Care Retirement Community**). Um, and my mother had seemed amenable to going there at that point but I guess dementia had already been setting in by then, and at the same time that Andrea was trying to get her to move out there she was also like writing her out of her will and um, I ultimately (hesitates to find her words) I felt like I Andrea wanted me to help her get my mother out there but, I felt like she had to know that um and so I mean I told her and I (pauses) ultimately and I realized that for whatever reason my mother did not want to go to California. She had expectations of Andrea that were unfair. Because Andrea had this large house, she wanted Andrea to have her move in with her and with her cats and the fact that even though her husband is intensely allergic to cats and the fact that wasn't going to work for them was not really something that she could understand um so. For me, my husband and I combined two studios so there are no expectations (Dolores and Naomi laughed in unison) of moving in with us, um and she wouldn't want

to move to Kentucky because my younger sister has a son with autism and has enough to deal with and for a long time she insisted on going to a place that was far from all of us and it really hurt my feelings, every time she would say "I want to go out to this place in Texas, would you go visit it with me" and I am like "no, no" (laughter)

Dolores: do you think it had to do with her condition worsening or do you think, um or do you think it had to do with the relationship she had with her daughters? do you think that influences her position?

Naomi: um, I think is I think it was

Dolores: sorry (embarrassed)

Naomi: no, no is a good question it really is, I think it is both. Part of it is that she did not want to lose her independence and she also did not want to be a burden on anybody um, and I (hesitates) um yeah, I think but also there has been a lot of distance in our relationship um, and also at times with my older sister she probably had least distance with my younger sister um, but I don't think she trusts her judgment very much (nervous laughter) ah, so, yeah I think it was a combination of the two.

Dolores: was your mother a career mother or was she...

Naomi: yes, she was

Dolores: what was her profession?

Naomi: she was a psychologist Ph.D. in psychology and she worked for the Veteran administration for most of her life treating PTSD mostly in Vietnam vets. And she really loved the work and it really defined who she is, um,

Dolores: It must have been very hard for her to see herself change...

Naomi: you know, still is at times just like a week ago she said to me um something really terrible is happening to me and I had no idea what to say to that um, I so she still does have these moments of lucidity and is aware of the loss and for someone that has defined herself so much by her intellect, capacity to care for others I cant it just (sad voice) for anyone is horrible

Dolores: it leads me to the next question, it obviously affects you, aside from your husband who you already mentioned. who do you go for support, how...

Naomi: so, I have a support group through Caring Kind that meets once every other week, and that has been very helpful, and I have my older sister um and that's I mean the support group helps tremendously. It is so (pause) so helpful to have people that are going through at the same thing at the same time and really get the experience. my husband used to work in a nursing home, he is a nurse I mean...

Dolores: He does it professionally

Naomi: right, he still doesn't really get what it is like when it's your own mother.

Dolores: because has never experience that...

Naomi: right, yeah

Dolores: how did you find out about this support group?

Naomi: I, oh yeah. I had originally gone to the Alzheimer's association um, which is you know there was a split between Caring Kind and the Alzheimer's association which I was unaware of at the time and it looked like Caring Kind had most of the resources. so I had thought the Alzheimer association was all there was and they had these telephone support groups that I tried a few times but I felt that I really didn't fit in because all of the people in the group they were taking care of their mothers or spouses at home and having a very different experience and I kind of felt like i was being looked down upon(nervous laughter) um you know so that just wasn't a good match and then actually I took my

mother to the Center for the Aging Brain at Montefiore for an evaluation because I wasn't happy with the support services available through Columbia Presbyterian where she got her diagnosis, to say the least, zero support services and the social worker we met there (at Montefiore) told me about Caring Kind, and I was like wow, I had no idea that there had been a split and I contacted Caring Kind.

Dolores: so, how long have you been going to the support group?

Naomi: um, I think it has been about six months

Dolores: so, is been fairly recently?

Naomi: yeah, it is a small group there are right now only 4 of us, but it is a real lifeline.

Dolores: have you ever taken private therapy?

Naomi: oh yeah, many times. I have been in and out of therapy my entire adult life and so and of course I have been in therapy during this whole process

Dolores: so it helps to talk about the experience with your mom

Naomi: it does, the individual therapy was really helpful for me in dealing with the emotions. (hesitates) Things are so much easier now, my mother has become much more agreeable and pliable. we went through a stage where she was really angry, suspicious and mean, meanest of all to me and was saying horrible things about me to her siblings and her speech pathologist.

Dolores: was it very out character, she had never done that before?

Naomi: It was to a much greater degree. let's say that she always had the capacity to be mean I mean and (laughter) my father used to call her "mean Eva Jean" (laughter between Dolores and Naomi) so but now she is the most pleasant person on earth. everybody at the five star loves her, and they rave about how wonderful her disposition is and they say you are so lucky, I am now (laughter between Dolores and Naomi)

Dolores: maybe is the five-star place that changed her (jokingly)

Naomi: she wasn't like that when she first got there (laughter)

Dolores: maybe they are doing something

Naomi: maybe, um although, I hope I am not making a mistake

Dolores: you are not, sounds like you spent a lot of time researching and making sure, because even before when you were mentioning the doctors and the clinics...

Naomi: yeah

Dolores: it sounds like, I know that you said before that support group kind of looked down you weren't living with her but it sounds like a full-time job making sure that, is not like she is somewhere and you are living your life it sounds like you constantly

Naomi: yeah, yes! It's been a real challenge to , you know there is this book the 36 hour day, are you familiar with it?

Dolores: no

Naomi: It is like the bible for caregivers and yeah, that is exactly what it feels like. there are not enough hours in the day, It is like another full-time job.

Dolores: and you already have a full-time job...

Naomi: (laughter between Dolores and Naomi) i already have one exactly yeah and then but at certain point as hard as it is it would be there is always this recognition that it would be even harder not to be able to do this, to be in the position that my sisters are in, (hesitation) you are just observing from afar and um I am so grateful to be able to do something.

Dolores: do you think that your sisters feel more of a guilt or a burden because they are not more involved

Naomi: (long pause) they haven't articulated that

Dolores: but you feel that...

Naomi: I am just imagining that is how I would feel, um, on the other hand, there are all these complex feelings like Andrea is also a bit relieved. She said to me she told her husband "if mom moves out here that is the end of life as we know it." (laughter in unison)

Dolores: so, do you get a lot of nice gifts from your sister (joking)

Naomi: um, but they are appreciative

Dolores: acknowledge

Naomi: they do this , yeah, there hasn't been a lot of second guessing. You know, Andrea will say, it is your decision I will talk it through with you and be supportive but I am not going to second guess you.

Dolores: and your younger sister is less involved...

Naomi: yeah, yeah,

Dolores: You have answered a lot of the questions just with our conversation; may I inquire about monetary support? Do you support your mother or she cover her...

Naomi: fortunately, she does have a good pension and her husband's social security. Because she spent almost all of her adult life working for the federal government, she wasn't eligible for social security but she has a very good federal pension and her husband's social security and between the two um, and the bit that she had saved I have not had to support her, and I mean my goal is to try to ensure that her money will last her through the end of her life.

Dolores: so, you do manage it?

Naomi: so, I am managing her money, yeah
but I am not yet contributing

Dolores: but managing it could be stressful and making sure that this goes here and...

Naomi: yes, I am paying everything um, yeah

Dolores: do you ever, I know you cannot turn it off, but do you ever, are you able to go on vacation or

Naomi: yeah, i just went on a 20 day vacation, yeah, so I called her a few times from vacation she has reached a point that she rarely answers her phone um but I did get through to her a few times and I felt confident enough in the care she was receiving there that I got to go and not worry and not worry about her, yeah

Dolores: one question that i had was I have sort of a final question and then I would like you to tell me about what you would like to say. What do you think can be in the state on in CUNY to support caregivers like yourself, family caregivers, what you have seen out there paid caregivers i don't know if you had ever had an experience with paid caregivers unlike the...

Naomi: Well, I had to hire private aids to help her at the five-star, yeah and they have an agency in the building a private agency that they encourage people to use to supplement the care that they are providing um so I have been hiring aids through that agency. But to answer your question, what can be done (pauses)

Dolores: do you feel that there is something lacking currently in the support that is given in the state?

Naomi: I think, i do recognize that this state is better than perhaps the best state in the country in providing for people that are Medicaid eligible and the community Medicaid program is really a great option(long hesitation) I am aware that every day I am so

grateful that she has the resources to pay for the care that she needs. I think most people are not in such fortunate circumstances, and I really do think long-term care should be part of single payer health care system in NY state

Dolores: through your experience, what is something that you would like to share for someone that could perhaps be in your situation what do you when you heard of the Labor of Care archives what made you think of yes, I would like to somehow say yes I would like to contribute my narrative. Was there something in particular that you would like to share.

Naomi: I actually really wanted to participate in the playwriting and often I would think, is this something I would put in my play? (laughter) um but you know I don't think there is one thing I can point to um, I guess my inclination is that there is strength in the collective so I wanted to be part of this collective process so that people could draw strength from each other. um, there was a funny thing that I would like to share. I was showing my mother the pictures from Italy when I got back (holding back laughter) one of them was Michelangelo's David so I said "this is Michelangelo's David" she said "funny, that doesn't look like him" (Dolores and Naomi laughed in unison)

Dolores: they did say that he needs some (laughter again) restoration there, your mother...

Naomi: that was actually one of the reproductions and actually it was pretty good, so that was just so funny. I am just so supportive of the existence of this Labor of Care archive and the project that Kathlene has put together to enable people to come together and collectively process what they are experiencing and make art out of it.

Dolores: thank you, thank you very much, anything else that you would like to...

Naomi: I don't think so, nothing else comes to mind, I guess one other thing, I spent a lot of, actually I will share this thought. I spend a lot of time in the first, in the past 19 months half of this period feeling perpetually inadequate and then but I have been through yoga and therapy and the support group and over time I came to accept that I don't have, I don't have all the answers and the answers are never going to be clear and that all I can do is the best I can um, and that my yoga instructor yesterday said, we were talking about the distinction between pain and suffering that there will always be pain but there doesn't have to always be suffering and I was thinking about what that means and I finally came to the conclusion that I might have found that place where there is pain without suffering.

Dolores: that is so beautifully said I have to say and I think that will be make a difference in somebody because is

Naomi: thank you

Dolores: no, thank you. If you don't mind I would like to close with that is really so beautiful.

Note:

Exchanging emails hours later Naomi wrote me the following: There's so much I wanted to share with you. You are an amazing interviewer. I do have another thought about how caregivers at CUNY can support one another. Perhaps there would be interest in having a Google list-serve where people could post questions, resources, thoughts, etc. That could help to create more of a sense of community among CUNY caregivers

