

Interviewee: Marjorie Cohen
Interviewers: Shannon Birch and Alec Capstick
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Abstract:

Marjorie Cohen was born in Worcester in 1949. In this interview she discusses the tremendous amount of work she has done for families whose members have both mental and physical disabilities. Her daughter, Caroline, was diagnosed with Cerebral Palsy, setting in motion her continuing mission to make the world a better place for handicapped individuals. Cohen has led several committees in order to get the community together to help families care for those with special needs; she has also petitioned schools to extend educational and co-curricular programs to those who were denied those opportunities. She continues to work to make the world a place where everyone, no matter their ability, is given a fair chance at life and at education. Cohen discussed the struggles of being the mother of a child with disabilities and seeking the proper treatment and care that people with handicaps and disabilities deserve. Making the families of the differently-abled comfortable is equally important. In recognition of that, Cohen organized group events so siblings and parents could see that they are not alone in the struggle to help their children. Through her actions, Cohen demonstrates true love and dedication by caring for her daughter and others.

AC: Alright so hi.

MC: Hello.

AC: How are you doing today?

MC: I'm feeling very good, and excited too!

AC: Good! You should be. Alright so let's start with your general overview: your family, how long you've lived in Worcester

MC: Ok, now—go ahead you were going to say something else. [laughs]

AC: Right, so we'll start with...

SB: Your name.

AC: Right so what is both your maiden name and married name.

MC: My name is Marjorie Merakian Cohen, and, let's see, yes I've lived in Worcester all my life and, well let's see. I don't know what else to say. I grew up in Worcester went to schools in Worcester. Actually some of the schools in Worcester I went to are no longer around. They were torn down. There was Dix Street school... okay yes and I grew up off of Ormond Street which was a three decker and around when I was about eight years old we moved to—my parents built a home in the Bronkord area. And that's where I lived until I got married.

AC: And then you moved out here with your husband?

MC: Yes, that's when I moved here. Yeah. And, well, there's a lot in between there though. Should I just tell you that?

SB: If you like!

MC: Alright, well, let's see, went to high school, graduated from Burncoat [High School], and decided to go to art school, and so I got into the School of the Worcester Art Museum. A lot of people don't know that that was a regular school for 96 years. It was for three years, and either you went to commercial art or fine art and I did commercial. And then after graduation, about 1970, I was in the summer going to Quinsig [Quinsigamond Community College] for literature classes and I liked it very much. And a lot of people that go to the art museum school, they continue on to Clark University, so I did. I transferred there and took night classes and summer school as well I was working. And actually I grew up in the flower business. I had some commercial artwork that I did in different companies around the city but the pay was very low, it certainly is a lot different now. I was always working in my father's flower shop. I really started working there when I was about five years old making little bows and things and kind of sneaking around the corner, taking ribbon, and eventually I became a really good designer and I learned from the different people that he had employed through the years. And actually, through those years I was doing design shows around the state and in competitions and all and that was something that I really, really enjoyed. So I did go back to commercial art, but again, it didn't last very long.

I got married. We had a daughter right away, but she was nine weeks premature. And my daughter, Caroline, was diagnosed with cerebral palsy so that was something that, when you have a child with a severe disability, and she does, you really have to be involved in everything to do with her. We had to learn how to work with Caroline and we had a lot of issues. She didn't sleep and that kind of thing, and we went to UMass [University of Massachusetts Medical Center] for direction. Once she was diagnosed that's when they sent you to early intervention and we went to early intervention until she was three. And we learned about all the different things on how to work with her whether it was speech, physical, OT [occupational therapy], that kind of thing, and during that time they were looking for someone to take on a newsletter and so I decided well I might as well do this and it was really a way for me to cope with the grieving, all the things having to do with a child with a severe disability. So I did the newsletter and that was

for the different parents, and it was something that I also learned information to pass on. Well, that was sort of the beginning for me, because that's the sort of thing I've been doing for 38 years. Now Caroline's 38 years old, actually she'll be 39 in April, and through those years that's what I did. Let's see, now, I'm trying to think. So much has gone on, you know, you kind of forget. But I did go back to work at my father's, and it was good that it was my father's shop because I took weeks off on school vacations and summers off because I had to be with her all the time. There was no such thing as a good summer program for the children with severe disabilities. She went to *[inaudible]* school after preschool at Flagg Street and I was very very involved in the school and a real partner with all the teachers. We wanted to make sure that she was a bright girl and we wanted her to learn as much as she possibly could, and we had been reading to our daughter since she was six months old, if not before, just because we felt it was really, really important to nurture her any way that we could.

SB: Right.

MC: And I know this is my story, but my story is my daughter's story too. And she had numerous orthopedic surgeries from the time of three years old on. And when we did go to genetic counseling, we didn't know if we should have another child and it was shown that it wasn't a genetic thing, so we decided that we would have another child, and we did, we had our son, Michael. That was really a joy, and it helped in many ways for coping and just also for Caroline to have a sibling, you know. So I was very involved with the school, and since there was no summer program and I heard really bad things about the ones that they did offer, that really didn't have a component of academics as well as recreation, I decided that I would speak to the school committee. So I did, and encouraged them—and it had been mandated in the state of Massachusetts that children like my daughter had to have a 12 month program, but Worcester was not going to put out the money, the funding that kind of thing to develop something even better than—a better thing that they had. So that's when I did speak in front of the school committee to encourage them to do so, and I really wanted the academic model but more than she was having and everybody else was having. So that's when I really got to know Senator, well she's now Senator Harriet Chandler. And come to find out much later on that she was actually a cousin of my mother-in-law's by marriage. She has been a strong advocate and supportive for us as well as other people with disabilities from other families I have been—oh! I have a team of parents that, we've just come from early intervention to do a legislative advocacy, we go to the state house all of the time, I received an award for—I had a bowling league for 11 years for children with severe disabilities then it grew to children, teens, and young adults! My daughter went on to South High School. That lasted for 11 years, and I made sure that we had the equipment and everything because there was no recreation for people with such severe involvement, right? So I went over to the United Way and I bought a chute! And what a chute is, is like a T-bar with, they're like canals. You place a T-bar on the wheelchair and you position the part where the ball goes down on the lanes, and...

AC: I've heard of that!

MC: Yeah! And the people of United Way said, “We can do this.” So we involved the United Way as well as Carpenter’s Union, and they built a few of them. So as I said we used them for many, many years at Thunderbird Bowl, and they were not wheelchair accessible at the time, so when I went there to tell them about the league we were starting, one of the women who worked there, her husband said, “I can build that for you.” So he did [referring to a ramp]. And funny I just found, my mother-in-law as I said [referring to previous off record conversation] she’s in long term nursing now, and she kept everything, and I found an article that I had written about that thanking this gentleman for doing that. So I’ve been doing these things continuously. And the summer program, going back to the summer program, was very good and Caroline lasted in there I think maybe three or four years, but it was advantageous to other families and other students who came along the way, and now it definitely is available. I won an award for the bowling, at the state house, and then I became the recipient of the Gunnar Dybwad Leadership Award that Senator Chandler nominated me for.

SB: Congratulations.

MC: And that’s a really top honor for families or people who are in the community who are not legislators and that kind of thing, and community workers. So I received that, and every year I go to the state house on that particular award day, and they announce who did it and I’ve nominated people as well and you know many of us families who have come through the years learning and advocating because there wasn’t a lot of things years and years ago. We’ve made a big difference, and the legislators, they’re helpful, their family members too, some people have a real hard time talking with them and it takes—you have to kind of feel comfortable in your own skin to start doing that, but they are very supportive they understand the issues, you know, we meet them all the time. It’s a really nice relationship, and my husband and I supported many of them by going to fundraisers and things we’re able to do that, not everybody is. But, that’s our way of contributing to them as well. So, I have been on boards and mentored families through the years, I worked for Seven Hills [a human services network supporting those with disabilities] for a while, and there was a satellite office for the Federation for Children with Special Needs which is out in Boston which is a really good source for a lot of people. They had an satellite office building on Hope Ave. off Seven Hills so I worked there for about a year, helping other families too, and that was while Caroline was in school. I’d always have to rush home to be here to get her off the bus or the van because she went to a day program after she graduated. That’s kind of a long story too, because there was no such thing as a really good day program for students when they turned 22 and it’s the day of your birthday, her birthday, April 24, and that’s the last day she could go to school. Because there’s no funding after that in the school system, even though I supported them and advocated for the school and I’d be on radio shows and they’d have call ins for South High School and I tried to ward it off so they’d continue out at least until the end of the school year. Well, they wouldn’t do that. So since I was on the area board for Citizens Advisory Board for the DDS [Department of Developmental Services], and at the time it was DMR, Department of Mental Retardation, which is a really hurtful label, ok?

SB: Right.

MC: But I was on that for a few years, and our area director was very interested in trying to help me with this situation, because I wasn't the first person who went through this who didn't have anything after high school. And what would happen, I mean Caroline would just be home or I'd—and we weren't just home, I'd do things with her all the time. But it's exhausting! We didn't have a—she's total care, so we didn't have a lift for me to use for a long time. I was reluctant a lot of times, because I'd just do bodily lifts, but finally we did get a lift that was appropriate and I made sure that I could do it. So that was helpful but that doesn't mean that it—there's still responsibility there.

SB: Right.

MC: So, Peter Trayors, he was the area director of the Department of Mental Retardation, worked with me along with Seven Hills, so we designed a day program for Caroline and ended up opening to other women who were in the same situation and one of the women, I knew from her mom since early intervention. So on April 26, like a year and a half we worked on this design, as I said before, and academic and recreational component, and also community involvement because you want to have our people in the community so people will be familiar, and when I went to school there was no child with a disability, I mean we just didn't know what that was, and of course things changed since then, naturally, so more community involvement is very, very important so on April 26 we had the program starting. Two days after her birthday. Myself and two women, parents, we had to work quite a bit to make sure that this worked. I mean it didn't just happen even though we planned this.

SB: Right, of course.

MC: We still had to have our input and, well let's see, 15 years we're into the day program now they're over at the Aspire Building, which is by the airport that Seven Hills purchased about a year and a half ago, because the program at Seven Hills was getting very crowded and we still weren't having enough community involvement. Funding changed, because we had to go make sure around the state myself and a few other parents worked around the state to get families writing to their legislators to get funding. So that year was 1999 when Caroline had her day program so it started. There was a Chapter 688 that was supposed to be for after high school, but it wasn't funded. So it really didn't make any difference that we had that name, Chapter 688, it didn't mean anything. We got legislators to respond to our families that gave money. They did say it was going to be annualized, well three years later it wasn't annualized because something always comes up.

AC: They changed their minds real quick.

MC: Well they did and it was disappointing but... so there was less community activities outside the building.

SB: Wow.

MC: But Caroline adjusted and she was fine. But it did start to get crowded and Seven Hills was taking in more people from this initiative, it's called the... oh, what's the name of that? I should know, it will come to me, but there was an initiative, and there still is for people who have disabilities, and our families sometimes didn't appreciate this, bring them out into the community and into a community situation, in other words a day program not stay in the nursing home. So that was starting to happen. It's called adult day health. More elderly or older people were coming out of nursing homes and coming into these programs, then they also got residences as well, around the state. And that's really wonderful. My daughter—I mean a nursing home is what we used to think that maybe—it was nothing we wanted for her, and there was no reason to. She went to Disney World six times, she's travelled to Minnesota, I mean she travelled! We took a cruise with her, and we educated her continuously through the years. One of our things is, we went to presidential homes around the country, and libraries, and we're book people, and my husband and I actually opened up a rare book store for a while in Worcester and we collected books through the years and I mean this is something we did with her and my son! So we didn't want her to not have any stimulation after high school. That's crazy!

SB: Right!

MC: So anyway, the high school thing is another story, but, so anyhow, that's what was happening, people were coming out of the nursing homes and so many of us few parents said that we need more for our daughters and our sons to have more possibilities, more options, with the day program. Finally they listened to us. Took a long time, but then they told us they bought this building over at the airport and they renovated it and its absolutely beautiful and if you ever have an opportunity to go see it, just walk in and you'll see this wonderful aquarium as you walk in and it just is a really wonderful facility. There they have woodworking, and of course arts and crafts, I did encourage in the beginning when she was at Hope Ave. the craft center to accept some of our students for their program, to do pottery or print making, because I did those things when I was in art school, you know? Worcester Art Museum were not accepting of our people, but craft centers? They said, "Yeah we'll try that." Well, they were there while the funding lasted at least three, four, maybe five years and I can even show you some of the pieces Caroline made. She didn't have good hand control, but the things that they did are amazing. They are so proud of themselves! You know? And the teachers learned there that, oh, they can do more than people give credit to, you know? Just because you have an intellectual disability doesn't mean you can't do things too. So they would do print making and paper making! [laughs] Things I learned from her and then she'd explain to me that they did. The different types of firings from pottery. So I felt so good about that. But again funding stopped [laughs] but they had that experience!

SB: Right!

MC: It was great! You know? And they had so much pride and that makes me feel good.

SB: That's something she'll take with her the rest of her life, right?

MC: Oh! Absolutely! So, well, gosh I know I'm going on and on, but there's so much that I've been involved in to make things better. And like I was saying about the bowling alley, she grew older and the students grew older from South High School and all, so I arranged for transportation, we worked with the VMR at the time, to get some of the people to the facility, because not everybody has transportation. For years we've had an accessible van for her, but not everybody is able to do that. We've had visitors stay, we've had other family members come watch and I'd invite them to the city council and our area director of course and city council, nobody came except the mayor at the time [laughs] which was Mayor Hoover and he was quite impressed.

SB: Well that says something

MC: Yeah! I mean, it was fun for the kids, you know, that's all you care about. We had banquets at the end of the year too. I contacted the person who makes candlepin bowling balls, and it's right in Rhode Island actually, over the border, I think Smithfield or something.

SB: Oh yeah!

MC: So, I contacted him, I'm great for writing letters by the way or so I thought, and he said, "Sure I would donate a set," and gradually he donated a set every year and we would pull names out of a hat, but by the end of our 11 years almost everyone had a set of bowling balls. And you could get them inscribed! Caroline was using her grandmother's and we took her grandmother's and put her name on it, that was like really special you know? So everybody got theirs inscribed. They were having a good time! The nicest thing about that was fathers did not... fathers were always home taking care of the children while the mothers went to meetings and that kind of thing, because we went to all kinds of meetings, so Saturdays fathers would come and they would see that, "Oh the other fathers are just like me!" They're normal people who just so happen to have children with challenges. That makes me really feel good.

SB: That's inspiring.

MC: I think so and many of us are still friends for years and years and years and they know each other. And then we have the siblings too, because I figured I have my son, Michael, so I think Michael he was like ten and he took care of the siblings. They had bowling—two lanes of bowling that they bowled with. And that's nice because a lot of the brothers and sisters, they felt embarrassed. They didn't know. Maybe they didn't go too many places because their brother or

sister didn't go out much, you just don't know. But you know they get bullied - oh yeah bullying, a big thing with everybody.

AC: And you got everyone together, from the whole family in a safe environment -

MC: Isn't that wonderful?

AC: Doing something together I think that's amazing!

SB: Marvelous

MC: One young woman, beautiful young girl, had a trache[otomy] she had to have a nurse come with her she was from the Holden Hospital. We got her to come, and you know, she passed away, but she came and she loved it and in her obituary it mentioned the bowling and we would then see her uncle, he worked for the city and when we go at the dump [thinking of proper name] anyway he worked there and he always remembered me. And my daughter when she was still living with us, they would all come, but she enjoyed going to the dump very much because he always remembered us, which was really nice, right? It was in Ballard Street. So you know we made relationships, so yeah!

SB: Well, yeah, I mean, that's an unbreakable bond it seems like, that's really strong.

MC: Our daughters and our sons, more people know them than you can imagine. You probably have that too, but maybe your parents don't realize it as much as we do it's like, "Wow we know Caroline!" and "Oh I know Caroline!" and that kind of thing. So yeah, it just makes us feel good.

SB: So, your love for your daughter, and your passions for her, that's affected so many lives.

MC: I think so.

SB: That's, I mean that's really incredible. You sparked a whole movement for, not even caring for children with these disabilities, but carrying it out throughout their adulthood.

MC: We haven't stopped. It's a lifelong thing. So yeah. And I'm on the area board. Eleven years I've been the chair of now the DDS: Department of Developmental Services. I worked hard to make this part of many families work and self advocacy. They just really didn't like that mental retardation label. I didn't either. My daughter still is a bright woman, that doesn't mean she's a world scholar, but she is a bright lady, so why put them down. you wouldn't do that to anybody. So I'm also—I forgot to say, I've been appointed by Governor Patrick, and now Governor Baker and I'm on their commission for persons with intellectual disabilities.

SB: Wow.

MC: And I attend meetings at the state house. When that was a change from DMR to DDS I was invited to Governor Patrick's office when he signed that bill. That was exciting.

SB: That's crazy!

MC: A lot of things—I've probably forgotten a lot of stuff that I've done through the years.

SB: When you were younger did you ever imagine that you would ever be making and witnessing history like you've done?

MC: No. No. Many years, as I said, I'm great for writing letters, I got in trouble in junior high school about that. One of the teachers had given me a zero and taken my paper away during a test thinking I was talking to somebody, and I still say I wasn't, I was only 13 then, and so she had us right something about the word righteous. Righteous or righteousness. So I wrote this long thing and I got called down to the principal's office and I really shouldn't have. And we didn't swear in those days it was just like I felt that she wasn't fair, and I feel bad now because it was her first year teaching so anyway. So I got called down to the principal's office so my mom had to come down too and the assistant principal, Mr. O'Connor says, he knew that I wasn't a bad person, and he told my mom that I had a high IQ and I said, "Wow." I didn't know this. Then my mother says, "That's my Marjorie!" So he told her the situation. My mother said, "There's nothing..." Oh how did she put it? In other words there's nothing typical about me, I was always doing something unusual. Nothing is a surprise. That was it, but yeah, anyway, I guess that started it, and it made a difference.

SB: It has! I mean, you're challenging social norms, I guess.

MC: I guess! Imagine that. But I never thought that—my husband and I, we're healthy people! We wouldn't know that we'd have a child with a disability, premature, or anything like that, but it can happen to anybody, and we have learned that through the years. So, we're always available for other families. And my husband and I are very involved with our children and others as well and what I didn't mention was that Caroline—you got enough tape?

SB: Oh yeah, just checking to see if it is still recording [laughs].

MC: [Laughs] My daughter would not eat or drink at school. She had a bad experience at the age of 8 years old. It was a Mother's Day luncheon that they invited us to, and I noticed the teacher just kept forcing the food in her. She didn't let her chew! It was just like, the teacher was just distracted talking to me and other people. Well, she had a bad episode after that at the dentist, so I don't want to elaborate [laughs] so Caroline, I told her, "Just relax for a couple of days." That was a mistake. She wouldn't eat. She wouldn't eat at high school either and she'd eat when she came home, so I'd always have a nice warm meal for her, and that would be about 3 or 3:30. 5

o'clock she'd still eat another big meal. We finally got the day program, and she wouldn't eat. So, this was not going to work. Everything was really new, new staff and everything so this was a very new situation for everybody, but one of the staff, was new as well and took Caroline under her wing. That made her feel more comfortable, and it didn't just happen overnight. So as long as it was warm food, she's good. So years later, since I was on the area board for so many years, and then the chair, our area director wanted to do something for us special. They were going to be building a new group home in Leicester. He wanted Caroline to be a part of it. We were on the fence, but I always said to Peter Trayors, this wonderful person that we'll never forget, I said that I'd like this done while I can still advocate for her. While I'm still young enough. So, we still weren't sure ok? You know that's hard thing and your daughter and your son doesn't know that they're doing this because there's nobody to take care of them after we're gone or too old to do it. And I had back surgery at the time, right after it too. So Peter said go up, look at the land, time it and everything and yeah we did, right up in Leicester. We said we said, "Okay, we like the area." So good, Caroline's going to be the first person in this house. So I went there every day and took pictures of them clearing the land, then one of the modules came in, I have everything and I brought it to Caroline's house so they could have it to see. Well, I knew the eating situation was going to be a little difficult, so once that was built, a woman who was much older than my daughter at the time, Caroline was 26, she came out of the nursing home and she was placed there. She ended up being like the house mother at the time because she was like 60 years old and what we did is—oh and two other women came in as well—so there are four women there and they really didn't want to have more than that, and they all have their own bedrooms and it was a beautiful house, right across from the middle school. We'd go up about two or three times for dinner, just to get her acclimated, and that's a transition pattern that they do for just about everybody. So this looked okay. Well this was in June we said, "Okay Caroline can move in," and she was able to pick out her own furniture from Rotman's, they funded that, they had two choices, all that and it was fine. After that first night my husband was so reluctant, nobody believed this was going to work, and I was so determined she cried the next morning, we went right up, you know, and "Why am I here?" and all that but I said to Dave, my husband, "We're going to hang in there. Of course it's hard!" Well 13 1/2 to 14 years in August she's been there, and she doesn't want to come home!" She loves, oh, she's just so good, but we've always been there to support her. I cooked for the house every other week so she'd feel comfortable, and I did a lot of things, we did a lot to support it. We buy them things, whatever they need. I bring food up all the time. So now [laughs] she always wants to have her birthday there! We bring up pizzas and the whole bit. Now we were shocked. She always had to come home for Christmas and Thanksgiving, but not just the day, she'd spend the whole weekend. I'd be exhausted by the end of it, by the time you know, and she was coming home every weekend and that was until I had to have back surgery, and that was like two years into it. Now, this past year she wanted to have Thanksgiving there! We were like stunned. Who is this person? You know? "Really really, ok, Caroline, really?" "Yeah alright" so my brother, who is blind by the way, and hearing impaired, my brother myself my husband, we brought up some food they had made a wonderful turkey and ham and everything, we brought up other stuff. We had a nice time! And not everybody has family, so everybody can't go home, so there's a men's side next

door, it's a duplex for men, so they don't have families or they're just so involved their families can't do it. It was so nice and the staff was terrific and they cooked wonderful! So lo and behold she wants us up for Christmas Eve and Christmas! And I was like, I could not believe this. Really?! And we always had Christmas Eve at my mother-in-law's but she has dementia, so that was going to be a real problem. "Alright really? Really?" So we brought the whole meal up that time. I got it from Boston Market because I'm really great for doing things easy. So Boston Market, they were terrific! It was so good, and they had made stuff too. We had such a nice time! It was wonderful! And it was great too, because my house, I didn't have to clean. We got up, and after a few hours we left, and everybody was fine! We opened gifts there and everything!

SB: That's so wonderful!

AC: So she's moved on from being so shy and nervous about going there to she has become a huge part of the community there. She's -

MC: Happy. Really happy. So every year, a family has an ISP, and Individual Service Plan, and Caroline's is actually in a couple of weeks, and every year you try to think of different goals, and parts of her agenda for the day, past the day program as well as the house, so I have asked if— they weren't going out to nice restaurants and my daughter and I were very used to that. And I taught her really well. We eat out, we shop. We eat, out we shop [laughs] so they weren't doing a lot of that. I don't consider McDonald's and Walmart a good place so finally—Really!—after it just went on and on the other residents don't have that much money. They're all social security, it's what everybody gets. And they don't have families that supplement them like us. So finally I said I'd like to have Caroline out to dinner to a nice place with one staff once a month. Well now Caroline's going every Saturday and she's expecting this. Every Saturday with this one staff, Miriam, that she is just enamored with. Miriam is a student at Worcester State, she's from Liberia. She has a story that, you can't imagine. She lived through the different wars in Liberia and she was seven years old, and I'm going to mention her sometime to be interviewed because she has been by an organization that gave her a scholarship. And there's another woman, Anne, who is also a Worcester State student, and what is really wonderful is they bring the college life to Caroline and the other women there. And also other things like, Miriam is a biology major and Caroline loves watercolor, grew up with me and the flower business and knew all of this stuff and it just, what a nice addition who will speak to you on their level, like your ages [referring to interviewees, college freshmen] you know, to talk to people with disabilities because we all learn, we're all life learners and that's what I encourage for everybody, so that's been a wonderful relationship. It's just that someday she's going to be graduating and we'll see what happens. Oh I've been keeping track because I get up in front of the statehouse to different things and speak I keep this message that we've had a hundred and up to 127 staff that have come and gone through the 13 years and the reason being mostly because they can't afford to support their families and themselves many of them have come from other countries and they have to purchase both their car and their apartment and they don't have the family support and that's an issue too that I and hundreds of families around the state call the caring force of work done for a

long time to encourage legislators to support them and give them a higher hourly rate because they deserve it. And there are things that some of them have to do that, in a house like ours where they are total care that you, most people wouldn't do for a hundred dollars an hour. And I know when I say that, and I explain to the legislators exactly what I'm talking about what total care means. So we've had some wonderful ones and we've had some not so wonderful ones and it's just not for them!

SB: Right

AC: Oh yeah.

SB: I mean that kind of dedication isn't going to be in everyone, right?

MC: Yeah. So 127 we are up to. I also work as a partner with the Commissioner of Human Services, for a couple of years now, and that's one of the things she always likes me to tell people.

[All Laugh]

MC: What else, I know there's things but I can't put a book down can I?

SB: Well, I mean if you want!

MC: No, no, that's fine.

SB: Well, I mean, I'm just in awe. That's so incredible!

MC: I mean there were a lot of parents that do all this. We care about our kids! What parent doesn't?

SB: Exactly, but, I don't know, but, you... not many parents would ever expect to have to, I shouldn't say have, not many parents expect to give this amount of dedication to taking care of someone and bringing other parents in similar situations together for that, and especially with that whole group home and everything, I mean, I'm just, I'm in awe! That's -

MC: Thank you!

SB: It's wonderful!

MC: You don't have to be! But we do this and I think we've helped a lot of other families along the way because we're the older ones now and we do speak to some younger families.

SB: Right.

MC: I know it's probably not right, but I like to tell them that when we didn't start it wasn't this and this and this and you have this full inclusion that, it's really what's going on now, that didn't happen when our daughter started 35 years ago in the school system and I've worked so hard to get that, but then I sort of backed off a little because I thought she can't do this, and she's not able to do that physically. But you know I just try to get the message out there and one thing I do want to say is, when she went to high school, she was the oldest person at [inaudible] she was 17 when she went into high school and so I found out later from the last teacher she had that she was really the highest functioning person at [inaudible] cognitively and she always was very— she had great reading comprehension, and she's not able to read because her muscles in her eyes can't follow a page, but we read to her all these years, we read books constantly, and we read books and books, and not just children books. We started out naturally with that, my son was on the other side of me and we read and did flashcards and did all that. And then she listened to books on tape. I encourage other families to get talking books, which is from the Worcester Public Library, and they send you a recorder and then you can order all the different tapes. Once she was in high school, once I got her into the right type of classroom, she wasn't in the right one when I first went to see what was going on and observed a lot. Even though her previous teacher had written up everything about her, we had a meeting and everything we thought it was going to be fine, well they didn't put her in the right class.

AC: Figures.

MC: Yeah. So they, I'm sorry but she was with much lower functioning students. So I said ok I know my daughter, this is not appropriate. I ran around with the assistant Principal, Maureen Binienda—have you heard her name? She is possibly going to be the next superintendent and we hope so.

SB: Nice!

MC: And she was the assistant principal at the time. Came around with me to the different classrooms and looked at the regular ed! We listened to the different English classes and then I thought, "OK, this sounds right, OK, it was break time." I ran into class I talked to her quickly about my daughter and I tried to convince her to at least try Caroline for a week. Well, she was there for four years.

SB: Wow!

MC: Four or five years, yeah! And she did great!

AC: So it was a successful week.

MC: It was! She was in there four to five years. Until she graduated. And my daughter had really extreme surgery in between then and she had to stop, naturally, while she recovered and then she went back and she just picked up. She had an aide with her, to do the reading of the questions and things, and we did homework here. And yeah, they were modified, they weren't like really, really difficult questions and essays or anything, but she did very well and she got great marks! She was in a psychology class. The thing about that is she started to fall asleep, because it was pretty boring [laughs]. OK so we went on to something else and she went to a civics class, and that was perfect for her. I had tried to convince them early on to do that but she'd be the only student they would do it for. What a shame, you know? I always felt that even if you—I tried to explain to them that even if a person is nonverbal, you don't know what they're getting inside in their ears. You just don't know! And so you've got to keep adding, you know? And Caroline wasn't really verbal until she was six. She's really verbal now.

SB: A blessing.

MC: Yeah, it's wonderful. I love her. She's great. I have a son too, that I'm very proud of [laughs].

SB: Yeah! I was going to say! Yeah, how's Michael?

MC: He's terrific. He's really good.

SB: Does he -

MC: He's an associate professor.

SB: Oh wow!

MC: Yes, an associate professor at the University of Tennessee. Living in Minnesota, because—Michael went to Bancroft [School]. It was the best thing because we were really involved with public schools, but when Caroline was having the spinal fusion we needed him to go after school from middle school to his grandmother's house, which was this district, OK? And they wouldn't allow it. We had a big meeting and everything, the superintendent and they said no. We just couldn't understand that and we were pretty irritated, K? I wasn't happy with my 12 year old son being you know, what do they call them, a latki? What's the term when a person comes into the home with no family there? You know...

SB: I'm not sure.

MC: Oh! A latchkey kid. I just didn't approve of that. So we said "OK, the heck with that." So we took him, we sent him there and my parents were able to help us with the payments. It was the best thing we did for him. He was a really bright kid, and very gentle, kind man, boy. He'd

get bullied for it. But that's because he had a sister like Caroline. He was very sensitive about that and he was very kind to her.

SB: Is he as passionate about caring about the people with disabilities as you are, or has that passion carried over in any way?

MC: Well no, he has, but that's not what in, OK? But he's very sensitive to it, he is very politically involved and makes sure that's a subject in the topics that legislatures understand. And so, what happened with Michael, though, he went to Bancroft we went up and down the seacoast, the Atlantic seacoast to check colleges. Caroline came with us, to every one, Michael had planned out where we were going to go, all these colleges. That was really good for her too as well as for Michael, you know? And that was great and then he went with his father to the Midwest because we didn't want to fly out to Iowa and to Minnesota and they went out there to look at two schools and so he chose one and got into that. So he was out in Minnesota and—I'm trying to make this really short, so OK, when he graduated from there we went out with Caroline and everything, he decided it really wasn't a great time for jobs so he applied for graduate school, and he got into Harvard [University], so he went to Harvard and he received his Master's and Ph.D. there. There aren't too many jobs, isn't that awful? With a Ph.D.? So he did get a position, and I'm probably forgetting in between, at Rutgers [University] to help edit the Elizabeth Cady Stanton and Susan B. Anthony papers. He worked there. And that was completed after a year, year and a half, and somebody down in Tennessee was looking to do editing for the James Polk papers and he was recommended so Michael went down there and got the job over the phone. He lived there for about 18 months and did that. Then he kept writing to his girlfriend that we really didn't know about. They met in Minnesota at Carlton College, and they decided that after 8 years of writing, I guess they decided to get married! So the person who was the head of the project for the James Polk papers, said that he didn't really want to interview anybody else, he thought Michael was the best person for this, so lo and behold University of Tennessee allowed that so he has all the equipment in his home that he bought. He works in the house, but he's working on that in Minnesota.

SB: That's great, so accomplished a lot too, then! That's a big feat, going to Harvard in general, especially for a Master's and a Ph.D. But especially with the challenges of his sister and you always trying to help and always working so hard. That's incredible that he's... power to him.

MC: Well, that's our kids! You know?

SB: That's wonderful.

MC: Thank you. You know, I'm sorry but that's what parents do.

SB: Don't be sorry! It's what parents do!

MC: [Inaudible] That's what parents do.

SB: You really exemplify a true parent.

MC: Oh, well thank you.

SB: You're welcome.

MC: I'm proud of my children. And my husband is my partner. Both of us together. And that's not always the case in all families.

SB: Would you say your husband is a big reason for a lot of the accomplishments that you've made in the strides for helping people with disabilities.

MC: Yes. Yes. He definitely is. We've adapted our house many, many times and he had to do a lot of that. Well, Dave's right there all the time, so [inaudible].

SB: It's a woman's work, but really it's a teamwork.

MC: Oh yeah! Of course it is! And I know that there's a lot of other things but that's because we do things differently through the years, right?

SB: Right. See... I think we have a lot of information!

MC: Oh! I know! I'm sorry!

SB: No! Don't be sorry! We have about an hour's worth.

Alec: Don't be sorry.

SB: I mean, this story obviously, it needed to be out there. It needs to be heard.

MC: I think so.

SB: So many people, "Oh, if only there was a thing to help our child," or, "If only there was something." I mean, you had the courage to go out there and do it and get a band of people to help you with it. So

MC: Well, you do what you have to.

AC: You have done much more than you have had to.

MC: Oh, well accessibility is a big issue, you know, too. Encouraging that is what I'm saying.

SB: Right! So, congratulations!

MC: Oh! Well thank you!

SB: So I think—do you have any final remarks that you'd like to make, any final comments that you want the world to know?

MC: You know, I've read those books and every woman has something at the end, and I'm saying, "Well, what can I say?" I don't know! Just feel proud that you're a parent. My daughter votes, by the way too.

SB: Good for her!

MC: Oh yeah! Well there's no reason why she shouldn't! That's why we're not her guardians, per se, there's a lot of changes in the guardianship. Many of the people do have guardians because years before that was a thing. We just didn't want to do that. Well it takes away your civic rights, you know. So we're her kind of guardians financial and medical. But she still votes and the last time it was the last election for President Obama, she went to the Leicester town hall where they vote. And they get a lot of self advocacy information and all, because of meetings at the house, she was at a meeting of the self advocate program at Seven Hills for a while and they learn all of these things. How to be a self advocate. So she had gone in with her staff and, "I'm voting for Obama!" and she's [laughs] my girl. So I know a lot of the people working there as poll workers, you know, and they thought it was funny. That's good. That's good! You know?

SB: She's proud of herself!

MC: You know what else? I'm very, very politically aware of things, involved, and so I attended a debate with the local legislators for representative, the last time—I think it was like two years ago, a year and a half ago—anyway so Kate Campanale was running in place of John Binienda, who had passed away and he was our rep in this area and also in Leicester, and he was very supportive of us, for 18 years. So I wanted to go and be a part of this and I always enjoyed that anyway. So, Kate was there and I introduced myself to her, and I asked her—I wanted to make sure she knew about the group home, where it was and everything in Leicester. She told me that her mother was a special ed teacher! That really helped me like, ok she knows a little. So I said, "You know it would be really nice if maybe you could stop by and visit the house sometime and I know they're busy campaigning." [She said,] "Sure," and I gave her my information. Lo and behold I go over to Panera at White City—I'm known to be at Panera—so, who comes and parks in front of me is Kate and her friend. She said, "Oh we were just talking about you! When do you go see Caroline?" So I told her the days, Tuesday, Thursday, Sunday. "Ok, we'd love to go visit." So they did. So she came up and it was a pouring day, and I thought they were going to

like reschedule and no, so David and I went up and there, she had already come, sitting around the table, chitchatting. People don't think it's like a family. It is! It's a house! I mean there's a kitchen and everything. They were just chitchatting, and Joanne, the older woman, who is a really good friend now. We're friends, ok? And she was asking her questions, and she was also telling her what her day is like and that's important for a legislator to understand. Anyway that was really a nice thing. Then before Christmas Kate came up, dropped off some Christmas cookies. I know, huh? And then, we voted for her and everything, and she won! So I went up to the house that day, and I work at the polls, the next day was Wednesday, and I guess Joanne, they're supposed to read the paper to them, but I don't know, we buy the paper so they'll read it at the house, but anyway, I told Joanne that Kate had won. She was so thrilled! Its makes them feel like they participated in this, you know? They had a voice! And they made their voice count!

SB: Right!

MC: And that's powerful for anybody, no matter what, so yeah. It was good. They felt so great! They feel like they knew her! Like hey, we know her.

SB: Well they do now!

MC: Well they do! So I've written Kate many times, see her at the Statehouse or at Target, and it's like we're friends. Isn't that something?

SB: Yeah it is something.

MC: We're all just people.

SB: Titles mean nothing, we're all humans, I mean we can make connections like that.

MC: And Harriet Chandler she's been wonderful to us. So we support her, and she's not even my senator. Senator [Michael] Moore is mine. We have a good relationship and partnership and everything. And I have taken programs at the statehouse too. A legislative seminar where for two days you go up and you go to all these programs and some of the senators and reps speak about certain things. And you can participate going into the chambers—senators' chambers—we can sit around and all and each one takes a part of where your community is, because we're from all over the state. Our subject was talking about bullying, and, wow it's just impressive that you learn these things. To me you're a life learner and that's what I want for my daughter and anybody else. So there you go. There's my quote!

SB: Alright! Life learner, awesome!

MC: [laughs]

SB: Wonderful! So thank you very much.

MC: This was fun.

SB: I'm glad you had fun, I did too.