Pat Barber, August 15, 2017, interview 100-MI, transcript, Indiana Disability History Project, Center on Aging and Community, Indiana Institute on Disability and Community, Bloomington, IN, https://indianadisabilityhistory.org

ORAL HISTORY VIDEO INTERVIEW WITH
MARY LOU MELLOY
AUGUST 15, 2017
INTERVIEWER: JENNIE TODD
VIDEOGRAPHER: PEGGY HOLTZ
RECORD ID: 100-DO

MLM: MARY LOU MELLOY
JT: JENNIE TODD
PH: PEGGY HOLTZ

[00:00:10]

JT: All right. I'm Jennie Todd. It is August 15th. We are in Indianapolis and you are?

MLM: Mary Lou Melloy, Cindy Melloy's mother.

JT: OK. You want to tell us a little about yourself and Cindy?

MLM: Cindy was born July the 15th, 1958. And on December the 24th, 1958, we were told that Cindy was blind and deaf and mentally retarded and that we should place her in a residential facility.

JT: Now, who told you that?

MLM: On that night when we went to pick her up at the hospital and to meet with the doctors, there were three doctors there, and they told us in this room, not in the hospital room but in a special room, that we should place her.

JT: And what was your response?

[00:01:10]

MLM: And my response was that they didn't know what they were talking about because I knew that when I dropped a cookie sheet, Cindy would jerk, and I knew that when we drove at night she would lift her head back and follow the lights. So, I knew-- so then I decided that maybe they were wrong. Who knew what they were wrong about. And so, a very unhappy, aggressive mother left the room.

[00:01:41]

JT: And Cindy was how old at that point?

MLM: 6 months old.

JT: Six months, OK. So, you bring Cindy home and talk about life at home when you brought your new baby home.

MLM: Well the night that we took her home from the hospital after they told-- gave us this horrible information, we had called my parents and we were going to their house to stay that night and we told them what the doctors had said. So, my dad immediately called the minister of our church to come and be there and he said it was God's will. And I say, if this is God's will, I will worship the devil. So, I was a very noncompliant parent, if you will. I couldn't accept what was being told to me and I've always been the kind of mother that was going to make it the way I wanted it on my terms not the way it was.

JT: So, you come home and how did you proceed?

[00:02:53]

MLM: Well, my husband and I talked about what we should do and we both realized that she was slow and we both realized that she had physical problems. We knew that. That was something we knew. So, we decided that my husband would go with the mental part of the problem and I would go with the physical, which meant that I went with Easterseals, we were living in Evansville at the time. And so I started working with the Easterseals people and Don started working with a group of parents that had some kind of programs. I don't remember what they were. They weren't very sophisticated for the mentally handicapped people.

JT: And so you got some ideas or support or services or-- when you work with Easterseals, what did they help you with?

MLM: Well, Easterseals had a program that you could go there and get-- sort of like a preschool. We could go get physical therapy, well when she was six months old, she just got physical therapy. And mostly it was sort of to help me deal with what I was going to have to deal with. And then, I'm not sure what was going on with the mental part of it because I was so involved with the other aspects of it. And then, we-- when Cindy was 16 months old, we took her in for an evaluation. And this young man that was the therapist said, “She has a vocabulary of 36 words.” And the only thing we knew she could say was num. And num, we didn't know what that meant but actually she was saying I want some, but we didn't know that he knew that as a physical or as a speech therapist.

[00:04:52]

And from there, we just started with-- she went to preschool and then we were transferred to Columbus Indiana. And when we went to Columbus Indiana, they had no services. So, I drove back and forth from Columbus three days a week for Cindy to go to a preschool and I had two other younger children than her with me. And they had a parent support group that we could-- on Fridays and we could talk about problems and this kind of stuff. And I remember when Cindy was really young, I took her for her physical and the doctor said, “Why don't you have this child potty trained?” And I said, “Oh, I can potty train her?” And he said, “Yes.” And so I went to Sears and bought all of this stuff to potty train a kid, this was my first child, remember, and that was on a Monday and on Thursday, my back went out and I was put in the hospital and had surgery.

[00:06:04]

And my mother came down to take care of Cindy and she saw all of this diapers and pull-up-- not pull ups but they had a different kind of thing at that time and she said, “Well, she must've potty trained her and we didn't know.” So, she put her on the bus to go to Crossroads-- or not Crossroads but the Easterseals place, and they got her out there. Well, this kind must be potty trained, and she was. So, it was a kind of a unique experience for us because we were first time parents, we didn't have a lot of experience. And so then we were moved to Columbus Indiana and we went out to the med center and she went out there and then we were transferred up here, and I started looking for a school and I went to every one of the school corporations in Marion County and I decided that it would-- I had applied Noble and their facility was not what I wanted and they didn't want us. Don’s on the board at that time and so I went to-- I decided Washington Township schools would be the easiest school to strong arm to take Cindy because there was-- we had a dual diagnosis, we had physical and mental, and we needed-- we kind of needed both but that wasn't done, so they agreed to take her on a trial basis but I had to drive her.

[00:07:35]

And I remember it was December the 5th and they call me, the principal of the school, and he called me to tell me to come in and I was ready to fight because I just knew that he was going to tell me this wasn't working out. But when I got to his office, there was a beautiful little red tricycle and he wanted to know if we would pay for the adaptive things so that Cindy could be taught to ride a tricycle. So we knew that we had her in and that we were going to be OK and that she would be OK. And so she went to school there till she was 18. They would have kept her three years longer but I didn't like the way they trained the older handicapped kids. They didn't teach him to think for themselves. And so I asked for a letter of exclusion and put her in the workshop at Noble out on Tibbs Street.

JT: So, let me backup. I like the way, you know, you're doing a good job just like [inaudible] can talk and talk and makes a lot of sense. So you said Don was on the board at Noble?

MLM: Yes.

JT: But they weren't going to take Cindy?

MLM: They didn't take Cindy.

[00:08:55]

JT: Why did they not? Why did they not-- why did they not take Cindy? Let me rephrase that. Because you were looking for a school also, right? Not--

[00:09:07]

MLM: We were looking--

JT: And maybe went to school.

MLM: Well, Noble was a school.

MLM: When we lived in Columbus Indiana, they ran an ad in the paper for people to sign their children up for kindergarten. And so, I took Cindy to enroll her in kindergarten and I was told by the principal of the school that they wouldn't take, they didn't serve children like Cindy. I told you before I was a feisty mother and I wanted them to say the word and he wouldn't. But when I went home, he called me and he said, “It takes 13 children for us to be able to start a class for handicapped kids.” And I said, “OK. So if I find 13 kids, it-- you'll have a class?” And he said, “Yes.” So, I went on a tradeshow where young mothers who listened all the time where they could get cheap furniture and baby sitters all this kind of stuff and I said to the people, I am looking for handicapped children. Would you please give me a call? And I had 33 calls. But the day after, I compiled my list and everything, we were transferred to Indianapolis and I didn't have the nerve to call the school and tell them we weren't going to come back, so I just kind of snuck out of town and I don't know if they started classes then or what, you know, so.

JT: But then you also said that when you moved to Indy, your husband in on the board of Noble and then say we can't take Cindy, did they tell you why?

[00:11:00]

MLM: Well, their facilities were not good for Cindy. The-- there were steps everywhere and the parking lot wasn't paved. To be honest with you, it wasn't what I really wanted. I wanted her in public school, and so I just kept her at the med center getting-- because she needed the physical therapy and everything. And so she went over there three days a week while I went to all of the school corporations to see, you know, which one I was going to be able to strong arm the best.

JT: Great. I'm going to move my seat back a little. I’ve been sitting too long. OK. So, after she gets out of school, can you talk about what happens then?

MLM: Cindy went out to the workshop out on Tibbs Street. Well, in the time that we were there-- before we-- while we were in public school, I said to Don, he was actually president of Noble at that time, and I said, “Don, Cindy's got to have air conditioning and these kinds of things.” And so, a building was built. The parents all agreed with us and this-- the workshop as it exists today was built. And so, Cindy went there. Until we had an executive director that was really ahead of his time and we didn't like him because he was ahead of his time and it was changed and we were afraid as parents, and they started talking about doing a way with the workshop and integrating handicapped kids into the public. And I-- Don and I personally sent all of the parents a letter objecting to have a big meeting to fight this.

[00:12:59]

And after we had the meeting, the next morning I called and I said "OK. Find her a job." And that's just exactly, if you think this is work, you're the professional, you find her a job. And about 2 weeks later, they call me and Cindy went on a job and she worked there for 20 plus years and it just went away the first of January this year when it was being outsourced to Plainfield. And so, she has successfully worked in the community for 20 plus years and it was the way for Cindy to go.

[00:13:44]

JT: Can you tell me about the job and about the company and-- the experience working in terms of co-workers and just--

MLM: The company that she went to work for was Roche Pharmaceutical. I think it was called Boehringer Mannheim when Cindy started. And she-- the first job she had was some kind of sorting of papers to put in packaging where they were sending out promotions on a product that they had and then it changed and they moved to another building and they did a different kind of a job and then they moved to another building and the final job that she had was recycling diabetic monitors.

JT: Did she work full time?

MLM: She went to work five days a week and she worked six hours a day.

JT: How did it affect her benefits? Is that an issue?

MLM: It wasn't an issue. The benefit just were not affected by-- she's very accurate at what she does but she's also very slow.

[00:14:54]

JT: OK. So in getting the job, did she-- how did she feel about having a job, getting the paycheck? Did she have friends at work, that sort of thing?

MLM: Cindy-- It was the most wonderful opportunity for Cindy and I will tell you that there are other mothers that had children the same age as Cindy and they were afraid to let their kids go out in the community and my statement to those mothers was you don't have the right to deny them the opportunity to try this. And several kids did go out because of Cindy.

JT: Now, did she become friends with any of her co-workers?

MLM: Cindy has become friends. [Phone Ringing] I've got to do that because Cindy is out.

JT: OK. Got it.

[00:15:48]

MLM: One of the nice things about having a company like Roche and they're a top company to deal with, in the environment that she's in, Cindy has asthma and it is an absolutely sterile environment. And so it was the perfect match for Cindy. And Cindy still keeps in touch with the kids that she worked with. They have all gone on to different things. I think one or two went up to Janus, one of them is on a cleaning crew, and I'm not sure what happened to one of the other boys. The interesting thing of it is, on Cindy's birthday, one of the girls called Cindy to wish her a happy birthday as did a girl that Cindy had not seen in 20 years but she knew her from the workshop and she called her to wish her a happy birthday.

[00:16:50]

So they do have, if you provide them with a way, they do have a way to make friends and having friends is one of the most difficult things that a handicapped adult has.

JT: Twenty years is quiet a career.

MLM: Mm-hmm.

JT: You know, that's a long time to have a job.

MLM: And she made friends. The-- her-- the man that was in charge of the building where she was at Roche has been over here to see her, has brought her candy. They-- she has friends that worked at Roche. They have kept up with Cindy.

JT: That's fantastic. Well, that's where we make, you know, friends as where we spend our time.

MLM: That's right.

JT: So that's really good. So, how did Cindy take the, I guess, buyout or down-- downsizing of the company?

[00:17:48]

MLM: It's been very, very hard. And for the first-- just until the first of this summer, she had nothing this winter. Now, of course, we keep her busy. We take her places and do things with her. And-- but it's not the same as having her own things. She needs her own things, you know. And I think that one of the things that's really neat about-- Cindy doesn't really know the value of money or anything, but she really liked going to the bank to cash her check. She likes doing that. Now, what has happened to Cindy is we have gone to having people come in and take her out for about four hours at a time.

And one of the things in going out like this week, the girl will come tomorrow and she will go and I don't know what she'll do. I can't plan it. I can just give Cindy the money and I know that she has an agenda that she wants to do. The interesting thing that's happened this summer with the 3 new girls that we got, they have been teaching her to use an Apple iPod. And I cannot tell you what that has meant to her. Yesterday, we were outside just sitting out and enjoying the day and we came in and she somehow knows how to contact these girls with her iPod. And she had kept in touch with people that she knew. And they put numbers and names in that she wants to. I don't even know how to do her thing. And-- So it's been a good thing now.

[00:19:58]

Two of the girls are leaving. In fact, I-- that's what my calls have been like since you all have been here. The-- I'm getting a new girl and the background of the girls is what makes it so interesting. Cindy has had a girl that's going to IU, a girl that's going to IUPU-- let's see, she may be going to Indianapolis University, I'm not sure, but the girl that we're getting now is from-- she is a journalist for the National

Guard. And so every one of these girls brings a different background and a different-- it's just marvelous what each one of them brings to Cindy's life, the variety.

[00:21:03]

JT: [Inaudible] So, where does Cindy live now?

MLM: Cindy lives at home and her dad is 82 and I am going to be 80 in October and we asked her occasionally if she wants to move out and she says, no. Now, we have spent a lot of time, there used to be facilities called ICF/MRs and it was New Hope and North Willow. When they first came in to being, we made Cindy very familiar with those people and she went there a lot and then when group homes came into being, I have-- she has a friend that lives in a group home and she goes there for parties, and so she's very familiar with group homes and what they do, but she does not want to go live in one. And-- however, when I asked her if she want to go live in an apartment with a boy that she used to work with, she got-- she kind of thought she might like to do that. So I'm not sure that we're ready for that.

JT: Right, right. So, had she goes-- is she looking for another job? Has anyone-- is that--

MLM: Well--

JT: -- Noble

[00:22:28]

MLM: -- I think that the one girl might be going to be looking for another job, but Cindy is 59 and she has retinitis pigmentosa, which is tunnel vision and it seems to have gotten worse. And I think that as long as these girls can find creative fun things to do that I would just assume, unless the perfect job comes along.

JT: So that's not a big--

MLM: It is not a priority with me. No. No.

JT: OK.

MLM: But finding creative things to do in the community is. One of the criticisms that I have about-- so it's very hard. Cindy could benefit tremendously from having a swimming program, and it isn't that easy to find one that fits in. Your staff changes pretty often and it's kind of hard to get into a-- well, you can pay for something and then that staff person goes away and then you don't have it, you know.

[00:23:48]

JT: We've talked to a lot of parents that this is an ongoing issue whether their sons or daughters live at home or either they live in a group home, I'm thinking Dixie and Jennifer. The mom-- they're your all’s age and they say they just-- even though they have staff and they're 15, 20 minutes away, they feel like they are always on call, that they are always the first-- every time someone doesn't show up or every time there anything that changes, you know, they're over there kind of filling in and taking--

[00:24:21]

MLM: Well--

JT: -- care and just the turn around of staff is just, you know, they feel like they're kind of the bridge builder between the son and daughter and, you know, the new staff person again because they've just gotten into a routine or they've just gotten used to someone, and now there's someone new.

MLM: Well, staff is the most undependable thing and I feel certain that salary has a lot to do with that because when you can go work at probably Walmart or Panera Bread or some place and make the same money, I just think that's going to be an ongoing problem. I don't think it's going to go away.

JT: Mm-hmm. So, talk about-- you've lived here a pretty long time, right?

MLM: Yes.

JT: So talk about your neighborhood and the connection that that neighborhood has to your family and Cindy.

[00:25:19]

MLM: Well, Cindy is just like having anybody else in your neighborhood. They even new neighbors that we don't know kind of know about her because she's in a wheelchair, she's different, you know. So, when you're in the wheelchair, they remember her. Don used to take her out for walks in the neighborhood but I don't know, I guess we got old and we don't do that so much anymore. But certainly, the neighborhood has been-- they're there-- everybody is concerned about what are you going to do with Cindy when you can't do this anymore? We just had a United Healthcare, somebody that came out to check on things, and the first thing she says is, what are you going to do with her? And you need home health care [chuckle]. You know, and everybody is always got an opinion of what you need, but they don't seem to get it's not that easy to get that.

We do have the waiver. If we-- the big waiver that would allow her to go into residential if we needed it and-- but it's not that easy for us. We have not been able to let go yet, you know.

JT: So, what kind of changes have you had to making your home to make it accessible as everybody gets older and-- have you had to do anything or still just--

[00:26:50]

MLM: Well many years ago, we put handicap bars in both bathrooms and we do have a ramp out back, I don't think it's ever been used except by friends coming that can't get in any other way because we can still, you know, do things in and out with her, and you just have to make sure that-- well, we have all these security devices because social workers have told us that we should leave Cindy and we could go to the grocery store, or I could go get my hair done or something. And so we did what they said, we put in a security system, and we have never done that. We're never going to do that because that's not-- we're just-- we know I guess-- I think we know something they don't know but we haven't made a lot of adjustments to that other than the ramp and there is an alarm on the driveway when someone pulls into the driveway, there's an alarm that goes off.

[00:27:51]

I don't-- we don't encourage Cindy to go to the door by herself or-- and if Don's out in the shop, we have a little device that turns a light on so that he knows to come in and check on her, you know, and there's all kinds of little security things that we do, but they're-- I don't know that you had to do them and which is things we did.

JT: Right.

MLM: You know. And so-- but, you know, so far as Cindy is concerned. She has been very well received by society in general. They-- when these girls take Cindy out in the community, there are always people coming up and talking to them and from church and from the neighborhood and different places and they're always-- they kind of want to know who these girls are, you know. So, it's kind of like somebody is watching out for Cindy, you know.

PH: I was going to ask, so when she was growing up and with her siblings, what life was like when they bring friends over?

[00:29:06]

MLM: You know, if anybody noticed anything, nobody said anything. Now that she went to a different school and then they did and, of course, I was always driving car pool, so I always-- she was just there, you know. She's just-- it's the way it is, you know, it wasn't-- I don't think we ever, ever had anybody that was unkind or rude. Now, we had some professional people. I didn't understand why when she was taking therapy that they did the same therapy for the kids that were stiff, that they did for the kids that we were trying to make stiff. So my dad designed walkers and all kinds of things to develop her. We were just always doing our own thing, you know, it was not a -- if we didn't like what they were doing, we did our own.

JT: Good. Well, I'm trying to think what else we can ask you.

PH: You talked about the death box.

JT: Oh, yes. Is that what your husband and his group made different--

PH: No, no, no. The death box you're talking about.

MLM: Oh.

[00:30:23]

JT: But isn't that the old memory--

[00:30:26]

MLM: That folder.

JT: Oh, oh yeah. I think [inaudible].

PH: Yeah, the death box.

MLM: One of the things that I called it a death folder, I don't know what else to call it, but if something happen to Don or I, everybody that works with Cindy, my kids, my neighbors, everybody knows to go to this one spot and everything is in there. Her birth certificate, her powers of attorney, her-- all of her relatives that might be involved with her, her trust fund information. Anything that you need to take care of her is in that folder. And I update it once a year to make sure that it is up to date. And one of the things that I think is quite important for that has come along since Cindy was born is the trust fund for handicap people. And I think that if it all possible, if parents should leave a trust fund for their children because there's things like dental, they fill and pull teeth, they don't do crowns, they don't do other things.

[00:31:48]

And then there's just-- you just need money to have fun with, you know. And so, her trust fund information is there. And now I understand I have not been able to get good information on it yet, there's an Able Account that is out. And it is not in effect in Indiana right now but I'm on it with my people that manage our money and stuff because that keeps handicapped people from always being poor. A handicapped person in Cindy's lifetime has always had to be poor because they could never had more than a certain amount of money. The Able account allows that to happen better and I don't have that. One of the things that Don and I have always done when we-- no matter where we went on vacation, when everybody else was going and looking at towers and taking boat trips and everything, I was looking at facilities for the handicap.

And what I learned was what I don't want. And I was fortunate to be able to furnish the first group home that Noble had and I was able to show it how I wanted it done. And so, I've been able to not just say I want it done this way, I've been able to make it happen. And I think that most creative things that come for handicap people come from parents. I think that the changes that are meaningful for them come from parents. And there are many, many strong parents out there that have done a wonderful job in building programs and making changes. Back in the late '60s, I did Operation Child Hunt for the information that we use to pass mandatory special education.

[00:33:53]

That's a very educational thing for a parent to do because you get into things that you never ever dreamed off, you get into a cycle of your used to your child but you're not used to somebody else’s you don't realize. And one of the things that I have always known that what happens to the least of these handicap people can happen to mine. So, when you change something, you have to take them all in, you have to do it for everybody, and that's why The Arc has been successful because they came along and they met the needs, the first group of parents that got together met their needs, but they had to meet the needs of all those out that weren't being served and The Arc was able to incorporate all over the state and do those kinds of things.

[00:34:53]

JT: So, did you get involved with The Arc pretty much in early days? I know it already started because you said that was like seven years before.

MLM: Well, my husband was the one that was involved with The Arc. He went around the state organizing Arcs, you know. And he did all those kinds because remember I said I worked with the physical part of it, and it wasn't until Cindy-- and I could get the schools to take Cindy. So I was able to get that done. So it wasn't until Cindy was 18 that I really-- now, I did 2 national conventions and things to educate parents. I wanted-- I'm a controlling person and I wanted other parents to know what I knew. And-- so when I did a convention, I didn't do the way they had always done it, I did the things I thought parents ought to know. And so, I was involved in The Arc but in a different kind of a way.

JT: And when you say you did conventions, did you do presentations, you just--

[00:36:09]

MLM: No. I just got-- I'm not a presenter. I don't like to be in the public, but I knew have-- remember I told you, every time I went on vacation, I went some place and I can remember the man that we had come from, I think it was from Ohio or some place and he came and he did a luncheon speech for me one day and he had a potty chair and he was teaching parents how to potty train their children and the potty chair would sing, I can potty in my potty chair. And it would dispense M&Ms. And so, that was how they potty trained children. That was what parent-- I had found that out when I went some place. So, when I became aware of something that worked, I wanted everybody to know about something that worked, you know.

JT: So you were busy?

MLM: I was very busy. And Margaret and I met through the parent chapter and we have been friends all these years. And I can vouch for the fact that Margaret's daughter says, cookie, cookie, cookie, because one of the things that I missed -- so for handicapped people and I realized this very early on before Cindy was even old, I knew that the adults didn't have social things. And so, I started a Christmas party, this will be our 48th year of the Christmas party at our church and it's an evening party, and Cindy wasn't even eligible to go because-- but I knew it was something that I wanted to be the way I wanted it when she got old enough. So, Don and I have always worked to make things the way we wanted it to be before we got there.

JT: Yeah. That's smart.

[00:38:10]

PH: I had a question about the parent support group if you could talk a little bit about what it meant to have that group and maybe anything you might have learned?

[00:38:21]

JT: [Inaudible] each other.

MLM: Well, my best friend, she's the other Mary Lou, I met her through the parent group. We would never have met. She was living on the far south side, we lived up here and we would never have met except through the parent chapter meeting and I can't tell you what the friendship has meant over the years. And I have gone through-- she has placed her daughter and I've gone through that with her and I go through-- actually, I'm probably, I don't know, I'm on her daughter's-- if something happens to her, I'm the spokesperson for her daughter. And I think that it's nice to know that you have somebody that would speak up and that's from within the system that knows how it works.

And I get calls -- partial because of the Christmas party, but I get calls frequently from parents that I have known 20, 30 years ago that are facing a different time in their life. And they just need to vent to somebody that will listen.

JT: Do you feel like that support group or those opportunities that you have where you all met are still available to parents now?

[00:39:50]

MLM: I do not feel that parents today have the same support system. I think that when mandatory education passed and the kids went to public school, the parents could put all of this out of their mind basically till their child was 18 to 20 years of age and then they were suddenly just hit, you know, with lack of planning. And I think it's been very hard on them.

PH: So, can you think of something from transitioning in high school, you know, what was-- was there any type of transitioning from high school to--

JT: A transition plan --

PH: Yeah.

JT: -- where as Cindy was getting ready to age out of school, did the school counselor say, well, we need to get involved with voc-rehab--

MLM: No.

JT: -- and figure out a plan to--

[00:40:42]

MLM: You remember I told you I've asked for a letter of exclusion from the public school because I didn't like what she was going to be taught and I did that on my-- I've always been ahead of my time on what Cindy needed and I didn't-- Cindy has always had what she needed.

[00:41:07]

JT: So, some parents even though they transition out early, they say, OK, we're going to through voc-rehab and then voc-rehab does work around job assessments. They do some of that D and E work and then they still end up putting people into workshops.

MLM: Well, one of the things that I have-- when Cindy was in school, she was in an old house, and one side was the trainable children and the other side was the educable children, not allowed anymore but that's the way it was then. And I kept telling the parents that had their kids on the other side of the building, do not put your children in sheltered workshops, do not go to sheltered workshops. And my-- one of my really good friends who is 92 years old and her son is 60, she listened to me. And so when he got out of public school, he was on an experimental program that The Arc provided that they would pay half of the minimum wage so that a company would hire them. And so, her son took a job working for Washington Township schools as a janitor.

And so, he worked there until he was-- he had worked there 36 years. And they had put all of his money, and I always cautioned them against, don't accept entitlements. Your son can do-- he won't have to do this. Don't accept entitlements. And so, he drove a car. He learned to drive a car. He couldn't read but he had a-- they gave him a verbal test and he has retired with $750, 000 in the bank and he is-- he's facing. So, I think that there were times when you knew to tell people, don't do this. Once people gets use to entitlements, if-- even if their kid is high functioning, they don't ever give it up, they, you know. And so, if it is important to think ahead to know what you want to do with your child.

[00:43:38]

JT: So in his case, it wasn't you didn't like sheltered workshops, you just thought he didn't need it--

MLM: He didn't need it. That was the only thing that's where all of the kids were going at that time, but he didn't belong there. I knew that. It's like somehow or other several years ago, my name got on a list of autism list, I have no idea, but all of a sudden I started getting these calls from 55 to 60-year-old brothers and sisters whose parents had passed away and they were left with a sibling that had autism. Nobody-- they had jobs. Maybe their dad owned a company or something. They had no idea what to do with them. Well, neither did I, but we got them in the right vein to help with their problems. And so, I think it was important to plan ahead.

[00:44:38]

JT: That's a very good story.

[00:44:40]

MLM: When Cindy was five, I marched with the wheelchair and a sign saying support line item of the budget and when I came home that night, it was Lincoln's birthday and so there were bands there and there were all kinds of things there. And we were watching the news and my son said to me, "Mom, how could you? I can never ever go to school again." [Laughing] Because there's this mother who's carrying a sign. So there have been some-- there have been some-- I have to tell you that having a handicapped child while it wouldn't be for lots of reasons you don't want them to be handicapped but it has been an experience that-- it's like none other. I mean, we met people, we have done things that we would never ever have done.

Now, I don't know what's going on with a younger parents and I don't know if they're able to do these things, you know, but I can remember being in Montreal. The year that they announced that amniocentesis had been I -- was it wouldn't develop or they were going to use it-- it could use to diagnose handicapped people. [Inaudible Remark] And they were probably 5000 people in this hall and they were all standing up and cheering and I remember standing or sitting there and tears running down my face and I thought, who would want to know for nine months that they had this problem facing them? You know, I wasn't as excited about it as maybe other people would have been. And I-- but I don't think that having a handicapped child is the end of the world I just think you have to do a lot more planning.

[00:46:47]

JT: So the doctor that gave you that dreadful news or bad advice, what would you say to him today?

MLM: I really think he was a very-- the reason I had this doctor is I was a nanny when I was in college. And the family used this doctor who was a very prominent pediatrician. And I think that he was-- he just didn't have any idea, for one thing, he didn't have any idea of the maternal instincts that you have towards having a child, that's one of the things. And-- but he was a good doctor, and we did keep going to and we did not give up on him. Cindy had a concussion one time and I was-- we were down at the old St Vincent downtown and the doctor said to the nurses, this is what handicapped people do. And I said, "Oh no, this is not what handicapped people do.

[00:47:54]

What is wrong with you?" Well, she was in the hospital for 3 days and then as soon-- she went blind and as soon as the concussion passed, she could see and she was her old sweet self and everything. And so, they called the doctor and he said, "well, she can go home." And I said, "No, I am staying here. These nurses are going to know that that's not what handicapped people do." And I think we've spent a lot of time having to educate the medical profession-- professional people that worked with kids, you know.

[00:48:31]

JT: So this doctor has seen Cindy work for 20 years too.

MLM: Well, no because that was in Evansville and we moved up here.

JT: Oh OK, that's right

MLM: So, no. But I don't think-- I think today that people are more accepting of handicap people although they weren't really unaccepting of Cindy, but Cindy was not a threat to anybody, you know, she was just a cute kid, you know. So she wasn't a threat. And-- but I just-- Sunday morning in church there was a young woman that goes to our church, she's not young, she's younger than we are but not young. She lives in your neighborhood and you had a neighborhood block party, and she was saying how she enjoyed seeing Barbie. And so, you know, I-- she knows that we know them, you know, but she came up and had to make a point of telling us that, you know. So-- but I think so far as things I would like to see happen, I would like for them there to be more socialization available.

And I don't know how to describe this, but Barbie's socialization needs are different than Cindy's socialization needs. And I'm sure that she needs as much as Cindy does, but I don't see that being developed or dealt with at all now.

[00:50:17]

JT: Right, right, right.

MLM: If you don't do it, it does not happen. There are lots of things that happen for these kids and they happen because the parents make it happen. It is not because of a program that makes it happen.

JT: Well, one of the reasons that it doesn't happen through a program is there's no funding stream attached to it. Like there's money to pay staff to help someone find a job. There's money to pay people to learn daily living skills. Those sorts of things but in terms of being part of the community, volunteering, making friends, taking, you know, people to the-- there's no funding attached to it. And that's been an ongoing battle that many organizations have said. If everyone wants this, we can't do it because the staff are attached to billable hours. You really have to do so many things just to, you know, earn money.

[00:51:17]

MLM: Kind of I feel-- I have a probably not a popular feeling about money in that area. We get social security for our kids, we get Medicaid to pay for things, and unless the family is indigent, there's not a reason in the world families can't be expected to pay for those things. Now, that is not a popular opinion, I will tell you.

[00:51:48]

JT: Right, [inaudible].

MLM: But it's how I feel that Cindy loves to go to Beef and Boards. She's going Saturday night. And yes it's expensive and yes I do have to pay the staff person’s way to go, but that's what her money I think is for. And so, I think an attitude towards entitlements probably out of change a little bit.

JT: Well, you know, that's just been on going thing because a lot of people do want to do those things that may not have family support or may not have, you know, money and that's always the reason that staff tells us that they're not out because there's no funding.

MLM: You know, there used to be things like civic theater used to have a night when they were having their dress rehearsals. You could take kids and go to those kinds of things. I don't know where all those programs went, you know, there were some good things that we used to do. They used to have-- Noble used to have a trip that they would take once a year, kids they go to the World's Fair, they'd go to Florida, you know, different places. I don't know what made that go away but it went away. And I think-- I kind of think it has to do with, well I know what has to do with funding but it also-- people have to pay their own way, you know.

[00:53:23]

JT: Right.

[End of interview]