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**ORAL HISTORY VIDEO INTERVIEW WITH
MARGARET BLOME
AUGUST 15, 2017
INTERVIEWER: JENNIE TODD
VIDEOGRAPHER: PEGGY HOLTZ
RECORD ID: 088-DO**

[00:00:10]

JT: OK. I'm Jennie Todd. We are in Indianapolis. It is August 15th and we are here today to interview a couple people. And today, we are with?

MB: I'm Margaret Blome. I have a daughter who was born blind and brain damaged for reasons we do not understand, she hemorrhaged. Barb is 55 years old and she attends Noble on the east side of Indianapolis. I am from Indianapolis. I didn't get that in there.

MB: She attends Noble. Barb was born in 1962 and at that time, there was very little available for people were multi-handicap. One of the earlier things that I did was go to the School for the Blind, she was a year old. They don't take children that handicapped. They were very nice and explained these things to me. They sent me home with a book called "No Place to Go" and it was a story of a child who was born blind and brain damaged and the fact that he had no services. I did go to Crossroads which is a rehabilitation center here in Indianapolis and one of the early things we started doing was crawling patterning.

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And she also was taught how to drink from a straw and various other basic essential things. Barbie finally started crawling on her own when she was around three. She did not take her first independent steps until she was five. She loves to take walks now. When-- we've done a lot of walking over the years. When she was coming up the kindergarten age, when she was five, I thought, well, it's time for her to be in a program. And I went to Noble and they'd never had a blind child. And then, I did say to them, well, if you have a normal child who's not functioning up to date, you hire a tutor.

Indiana Disability History Project

Indiana Institute on Disability and Community
1905 North Range Road, Bloomington, IN 47408
indianadisabilityhistory@gmail.com | indianadisabilityhistory.org

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So, one of their staff person started working with Barb. She live not too far from the time she started but then she moved to the south side of the city. So, I drove to Southport twice a week for her to work with this teacher, this staff person. But I still wanted her in a program and finally, the therapist at Crossroads said, well, have you tried St. Mary's Child Center? And I thought, I read about it in the paper, but it sounded like it's something that would fit Barb. But I called them up and we went down to the child center and talked to the director. It was a very new program at the time. With one professional staff person, the rest were all volunteers. But the director said, I have some other parents that have problems finding services.

So, there were a group of us, mothers with child, who met together twice a week for two years. And we really became a support group. Then Noble took Barb when she was seven and she went half days and except for a few weeks I drove her. She was half days for about two years or two and a half years and Noble then had built a new building and she went full days. When she was 11, mandatory education finally happened. And so then, she was with the Indianapolis public schools for the next eight years and finally had bus service, which was wonderful after all that driving.

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And she went through Cold Spring School. And at that time because it was new, all the kids with disabilities went to the same school and there were, I think, 300 kids there, quite a few. And she had a really good experience in that program. Then she aged out of it. She was 18 and I had no services for a year and I really dreaded that year. But it turned out to be a blessing because my youngest daughter was a senior high school that year and she is my music and sports person and she ran track and cross country.

And always before, if I go pick up Barb early to go to a track meet, she would not want to go to the track meet because she was tired. And this year, that was the highlight of her day to go to the track meets. And she's very fond of music and we just went to a Beatles concert at Conner Prairie. Beatles are her favorites and there's a story behind that. When she was about two and a half or three, we went through a period where she'd have a week or so where she would cry her every waking moment. And I figured it was because she couldn't move around very much. She still wasn't walking. And she just had all that energy that people have and no outlet for it.

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And that was when the Beatles were very popular and they'd done a concert here and so I went out and bought a Beatles record. And it really helped. And our son who was about five at the time, and I don't know how he knew this, but he said, "See, music does soothe the savage beast." Then, Barb went back to Noble after her one year with no programming. And I called Noble regularly during that year and I would say, "Well, I'm curious just where do we stand on getting Barbie back in?" And don't know whether that annoyed them. They knew what I was doing, I'm sure.

[00:08:49]

So, she's been at Noble ever since and she has done well. She loves music therapy. I'm sure she spends time sitting because you don't have enough staff to keep people busy all the time. Noble had a very good parent chapter for a long time but that is no longer there. It was also kind of a support group but like a lot of organizations, us older ones are were getting older and many have passed away and the younger ones are working and taking time off to go to a meeting during the day, which is usually when we met. It just wasn't working anymore. It's a different era.

JT: You were saying your daughter had been there at Noble ever since and she was doing well at Noble and you're kind of talking about what her life is like at Noble.

MB: Mm-hmm, mm-hmm.

PH: OK. I'm ready, yeah.

MB: Yeah. Well, Barbie has done various things at Noble. And different staff people have brought her different activities. And over the years, things have stimulated her to do certain things. And one of the things she likes to do that she learned at Noble is to ride a stationary bicycle. And she loved it when they had pool. They had an accident at the pool so it was closed. In fact, that room is now the art room. They covered over the pool. But she still loves to get in the pool when we take her.

[00:11:06]

In fact, one summer, she had some birthday money and I thought, what am I going to do with this birthday money so I hired a-- not at Noble but at another pool, a swim teacher to work with her. And she enjoyed that. She more recently, as I said, has been doing a lot of music therapy. And the music therapist send me their notes that they have to send to Noble for their records. And they take her for what they call a musical walk which is a walk around the building or in the sensory garden while they play guitar. They had -- do amazing things with iPads. They offer her choices on the iPad.

One of them has a rubber band down the middle so she can feel the two sides and has choices on either side. The other one just showed her with her hand where the choices were and she could find them. And they ask her whether she wants slow music or fast music or whether she wants this group or that group and they play the piano while she shakes some rock, so-- or things of that sort. And so that's one of her highlights of the week. And they do get her out in the community once or twice a week maybe for a walk at the mall in the winter or in the park or whatever. A year ago in March, we placed Barbie in a Waiver Home. She has two roommates, they have three bedrooms so they each have their own room and of course a round the clock staffing.

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Barbie still rides bus to Noble. So, they're the ones that have to do the bus watching now. Bus watching takes a lot of time because it's never real prompt. And she adopted very well. Now, when she was younger and living with us, we used a lot of respite care. Our families are very spread out and when our parents were elderly, Bob's parents lived in Dallas, Texas and my mother was living in Wichita, Kansas.

And so, we made that trip twice a year because we didn't want to get old and say, oh, I've got a handicapped child, I didn't do anything, and besides, we wanted to see our parents. She comes home a lot on weekends because we want to do that.

[00:14:20]

But we're just grateful that we got it done while we are healthy. Now, as far as Noble, when it started, I was 10 years before I came into the picture. They-- see a couple of gentlemen and I can't remember their names, put an ad in the paper for parents who had handicapped children to meet, have a meeting at the War Memorial. And I understand, they reserved a small room and the crowd was so big, they had to move them to another part of the building. So, if you'd like to ask me questions now, I'd-- [laughing]

PH: I have wanted to follow up, you know, when your daughter was born, a lot of times the doctors at that time said, you know, they'd put them in an institution.

MB: I was fortunate I never had that happen, I know people who have. But my doctor said, I want you to take advantage of every opportunity you get. They never once gave me an opportunity. I mean, he just wanted-- I had to do the research in other words and that's OK. It's good for you to have to do something like that once and awhile.

[00:15:56]

JT: But there weren't a lot of resources available when your daughter was born?

MB: No.

JT: Your daughter was born, they didn't say, well, here's X, Y, and Z, you can go check this out. Here's are some support groups, here's-- you were pretty much on your own. And the book that they gave you at the blind school sounds just so sad.

MB: Well my son and daughter-in-law both work for American Printing House for the Blind in Louisville. My daughter-in-law taught in the Arkansas School for the Blind before she went to the Printing House and she tells me, every time you tell that story, it makes me mad.

JT: Yeah, I mean, it's very sad title of a book. And you know, to pass that on, it's not very helpful or supportive.

MB: I think, at that time, I just thought, well, that's an interesting story.

JT: I'm going to find a new book.

[00:16:57]

MB: Well, I don't think I thought too much of it myself at the time. It's just that they weren't any help to me at the School for the Blind.

[00:17:07]

JT: So, what kind of attitudes did the community at large have and your family and your friends, were they supportive? Did they-- what was it like 50 years ago? Sixty years ago?

MB: I think, overall, I was pretty supported. My parents said, you make your decisions and we'll support you. Bob's parents were a little like, I don't think you should have her at home. But, of course, that was the attitude at the time and before that. And they had more of a problem adjusting to it than my parents did. But, you know, it's-- I'm thinking that overall, I really had pretty good support. My neighbors have been supportive. I said, I couldn't move, I have to educate another whole neighborhood. [laugh] And I haven't had too many complaints about Barb.

JT: It sounds like her siblings were very loving and supportive.

MB: They were. Now they like also going-- had adjustments to make. I mean-- and I've only had one child at our house who made a bad remark about Barb and my mother was there and she told him, now that's not a good thing. And this kid was about five or six at the time. So, I can't complain about that. I had a group of Girl Scouts that came and helped me with the patterning when we were doing crawling patterning. And so, I've been very fortunate really.

JT: Can you describe what patterning is?

[00:19:18]

MB: OK. We had her on her-- the bed on her stomach, and one person on one side and one on the other, and you coordinate moving the arms and legs like you would if the child was crawling. And it's been 55 years, 50 some years and since I did it. But we did it for a long time. And the occupational therapist at Crossroads helped us with that.

JT: So, in terms of the vision issues, how did you learn to maneuver around the house and get around? Did you have support people coming in and doing that?

MB: No. One of the things that surprised me, when she finally learned how to crawl, she could come up to with an inch of the wall and not hit the wall. She apparently has very good hearing. We have movies, our other daughter who's almost two years younger than she is, of her, when she learned to stand, she had-- she spent one afternoon in part of the next morning learning how to stand up. Barbie did the same things. We've got movies during that year and when you look at them, you can see the similarities but it took her a whole year to learn to stand on her own.

JT: Did she have poor muscle strength as well? Or what do you think?

MB: I think it was just learning how--

[00:21:21]

JT: Her brain telling her legs what to do and--

[00:21:24]

MB: Mm-hmm, mm-hmm.

JT: OK.

MB: Yeah. She is nonverbal but she has a tremendous amount of receptive language. And she knows a lot about what's going on. But her favorite word is cookie and her next favorite word is dinner, [laugh] so.

JT: So then, in terms of language, how did she learn to --

MB: I think just by associating things and words and we didn't do a lot of language training, but, you know, we talked about, well, this is your dinner and this is a cookie. And we talked a lot with her. Now, she does need some help with eating. She can get a spoon to her mouth but she can't fill it.

JT: So, when you talk about learning these things, did something that happened at Noble and in the schools as well so they--

MB: Oh yeah.

JT: -- they were part of learning to move around and learning to talk or not talk but communicate?

[00:22:47]

MB: Yes.

JT: And process language.

MB: Mm-hmm.

JT: And all of that. So then, in terms of the actual Arc, when it started -- you guys came in a little later, so there's not really a lot that you would talk about in terms of that. So, in terms of services for people that had disabilities in terms of school and community and that sort of thing, do you feel like you've told us enough about that? Or are there other things that you'd like to add to what was available or what you felt was missing during the times when your daughter was in school?

MB: I think that programming has been a major help with us and there was so little for multi-handicapped child back in the '60s and '70s. And now, it's grown. There's a lot more opportunities out there and so I think we have been very fortunate that it has grown. And I think there's still room to grow but we also need to make sure we don't lose the services we have now.

[00:24:24]

JT: So when you say room to grow, what areas do you think need growth or need improvement?

[00:24:33]

MB: Well, there are so many variations with children with disabilities and adults with disabilities that that would depend a great deal on the disabilities that we're talking about. And so, in our case, I'm just extremely grateful that we have as much as we do today.

JT: Well, the word autism is something that we hear a lot of over the last 10 years and really more and more. So, when Barbie was a little girl, did you hear that word? Did they talk about autism much?

MB: No.

JT: Do you have any thought about that?

MB: Well, Barbie doesn't have autism, which is a blessing, however, I think it's kind of fascinating what I hear and it's a huge variation from individual to individual with autistic people.

JT: Right. It just isn't even term that I remember.

MB: No.

JT: That long ago.

[00:25:56]

PH: How's-- if you describe a little bit of what the school day was like and what did they do from the time they were there to--

MB: You mean, when she went to the public school?

[Multiple voices] Yeah.

MB: I really am trying to think, she went to public school in the '70s and '80s. Well, she finished public school in '81. And the Cold Spring building had-- let's see, it had two floors. She was in a room with lower functioning kids and then later, she was with a teacher who had her doing things like sorting different shaped blocks and things of that sort, which I thought was kind of amazing. And I'm not really real sure now of all the things her day was like.

PH: I was just wondering if, you know, she was involved with the general ed kids and maybe music classes or were they able to eat with them or?

[00:27:29]

MB: At this point, they put all of the-- the Indianapolis public schools had all the handicapped kids in one building. They didn't have-- it wasn't mainstreamed. And at that point, they began talking about it and then they began moving people in the different-- because they had very high functioning kids there as well as those with that were low functioning. So, they didn't have the opportunities to be with main-- regular classrooms. And so, eventually, they did and they closed the school for-- it's just a regular school now.

[00:28:31]

JT: So when she moved into waiver services, where did Barbie lived?

MB: At home. Well, she's has a waiver for Noble and then she has a waiver for the house that she's living in.

JT: So, she's always lived at home until she moved into the three bedrooms?

MB: Yes. Yes. She lived with us for 54 years.

JT: OK. So, this is new.

MB: This is new.

JT: So, how's the transition for you and your husband go as well as her?

MB: We were ready. Mm-hmm. So-- and the fact that we see her every week, I think, makes a difference.

JT: Great. And she was excited and just--

[00:29:17]

MB: I'm not sure she quite understood, she just adopted. And again, we had used a lot of respite care with several different providers but one in particular we used a lot. So she was used to being away from home for maybe a week or two at a stretch. Our other daughter who lives in Columbus, Ohio became ill at one point and she was single so I had to be there. And I left Barbie for the biggest part of a month and a half. So, she had experienced being away from us. So I think that helped.

JT: So, one of the things that you were saying that is different is that there-- because there weren't as many services, there were more support groups and you met with other moms and your children kind of on a regular basis in the early days.

MB: Just mostly through St. Mary's Child Center.

JT: But do you think, you know, with all the services now and parents that have to have both parents working or the single parents who have to work, do you think that the support that you got from those meetings in those early times is something that is really-- it's too bad that it's not there now. You know, there's more services with the support and talking.

[00:30:59]

MB: I kind of missed the parent chapter because we were supportive of each other, but as my other daughter and I were chatting not too long ago, First Steps would have been very helpful. Well, it didn't exist then, but it would have made life a lot simpler at the time just to have the professionals there that could give us guidance.

[00:31:30]

JT: OK. And then you talked about your neighborhood, you were saying you couldn't move because you'd have to break in a whole bunch of new neighbors, can you talk about basically the way that your family had to fit into the neighborhood and maybe how they knew your daughter and included her?

MB: Well, our neighborhood at the time we moved there had a lot of children and as you probably know, children and dogs help you get to know the neighborhood. And so, there were on the two blocks between Keystone [inaudible] on our street including high school kids, there were 35 kids. And so, the children kind of drew the parents together. Barb was out a lot and when she learned to walk we started doing a lot of walking. She, of course was at the house when other kids came to the house and that sort of thing. And several of us are still there after all these years, so of course, we kind of depend on each other.

Barb can be stubborn and she's gone through a phase where she don't want to get in the car, she wouldn't going to get in and she could make her body as stiff as a board. And several of my neighbors would be willingly come over, call them, Barb is not getting in the car for us. And they-- usually, she would get in for them, once in a while she wouldn't. And eventually, my daughter-in-law who is a trained teacher talked to a consultant who was a friend of hers who works with kids that have disabilities that don't want to always cooperate. And she, this friend, suggested that we bribe her with Fruit Loops.

[00:34:00]

And only give Fruit Loops when she got in the car. And that really went a long way towards curing this problem. Now, we still have occasions when this happens, but she only gets Fruit Loops if she is in the car in her seat no matter how she gets in the car whether we lift her in, which we have done or however she gets there and she only gets a couple. And so, sometimes you have to do these things. But my neighbors have been wonderful when I call and say, she won't get in the car, which is annoying.

JT: I can imagine.

MB: So.

JT: So you feel like she's-- you're connected, she's connected [inaudible] with support.

MB: And she's gone to the same church all these years and so she's known there as part of the church and so.

JT: Can she go to the church without you? Is there a bus or something like she gets to the church?

[00:35:14]

MB: Well, if somebody takes her, sure. And they have when-- on two or three trips since we placed her in the house. And I asked the staff to bring her to church because I think it's good for her to have that familiarity with and so, you know, as people church talk to her, that sort of thing.

[00:35:50]

JT: That's wonderful. Well, is there anything else you can think of that you would like to say in how attitudes have changed, how services have changed, or anything that we haven't already talked about?

MB: I think I've covered a lot.

JT: You have, you have.

MB: But you're right. It is very helpful that we have more services and it's very important to keep them.

JT: Can you think of anything that we need more?

PH: I mean we've-- we have people talk about barriers to getting appropriate services that you seem like you've--

MB: Well, we tried.

JT: Well, as you get older and your health changes, do you see other people stepping in who have kind of helped do some of the things that you and your husband are doing now for your daughter?

[00:37:01]

MB: My other two children are very concerned about her. And they can advocate for her. We have told them that there will be times, we didn't ask them, we told them, that there will be times when they will probably be guardian but they are not to take her into their home. That they need their own lives and they aren't to do that. But when we've had person centered planning meetings at her house, there have been a couple of times when they have participated by phone to know what's going on.

JT: And they're out of state, right?

MB: Yes.

JT: Yeah. So I thought you've said that they're kind of far away.

MB: One is in Louisville and one is in Columbus, Ohio.

JT: So, tell me about the person centered planning meeting? How did you think those meetings went?

MB: Well, we have them regularly.

JT: Can you get me-- can you talk about what they're like?

[00:38:10]

MB: Well, we review things that are going on. We talk about issues that are coming up and once a year, we have a budget meeting where we go over her waivers. And, you know, talk about issues that we need to resolve or have been resolved or whatever. And we have representatives from Noble and the house she's in is part of another organization called Tangram. And so, the house manager is there from Tangram.

[00:39:01]

JT: Yeah. The name sounds really familiar, is that Gwen Chesterfield?

MB: Yeah. Well, she's retired but yes she took over that organization.

PH: She's someone we wanted to interview.

JT: So, here's my question in the person centered planning meeting, do you feel like that Barbie's voice and her voice through you are heard and respected and the things that you want on her behalf are pretty much--

MB: I think so, pretty much, you know, so.

JT: So you're happy with them?

MB: I think that's I've been, over the years, we've had a lot of them over the years.

JT: Yeah.

[00:39:51]

MB: Yeah.

JT: Good.

PH: I guess, while we're waiting, how did professionals in the medical field, like when she had doctor's appointments, this is one area that we're looking into, as to how they treat her? Do they?

MB: I've had pretty good luck with doctors. The first doctor when she was really little was very supportive. I'm not sure he always knew what to do but very supportive. And we had several doctors over the years and they've been, I think, pretty, pretty supportive. I think that her dad and I usually go both, not always, but often both of us go to the doctor's appointment with her. And she still goes to Riley Dental Clinic and she's been going there since she was three. So, she's a fixture over there. She goes twice a year.

PH: Did she get other-- many other services from Riley as she was growing?

MB: No, no we really-- we had a few when she was real little but we'd mostly just went to our family doctor.

JT: So, can you tell us--

[00:41:25]

MB: Well, Barbie was seven at that time that she went to Noble the first time. And in order to-- it'd be at Noble. She had to have an exclusion. So, we went to the IPS psychology office and the psychologist took one look at her and signed an exclusion so that she could go to Noble. So--

[00:42:00]

PH: And how long was she there then because you said she was seven?

MB: She was seven and she was in the Noble for four years before the mandatory education started. And then she was mandatory in the public schools for eight years, home a year, and then back to Noble.

JT: Do you have anything you want to say about the mandatory education that [inaudible]?

MB: It was just a routine thing that they apparently had to do if you were school age at that time, I don't know what they do today.

JT: Can we talk about the lobby work that you did.

MB: Well, I don't know that it was a big thing. I went down when several groups met, The Arc of Indiana usually met during, especially the budget years, but the first time I went was when they were trying to get mandatory education into the public schools. And there were a lot of people down there supporting that bill. And that was the first time I was ever in the state house. So I found that kind of interesting, but I went back several times especially if The Arc was having a big meeting which they did sometimes. And nowadays, there's a group from Noble that valentines down to the state house.

[00:43:44]

JT: Well-- [Inaudible Remark] I was going to ask you to talk about your fun nights seeing the Beatles and then we'll let you go.

MB: Well, this past weekend, we did two parties, the Beatles, which are her favorite group with a group that does the Beatle songs was at Conner Prairie for the Symphony on the Prairie. So we went out on Friday evening, took our lawn chairs and we decided this year not to take a picnic, we just eat ahead of time. And went to see the people perform the Beatle's songs. And Barb loved it and she loves to scream when she hears them. So, she had a good time.

JT: Good. And then you had a block party.

MB: On Saturday night, we had a block party. A -- we had part of a block that was blocked off and the people who were hosting it at their house made sure we had the main dish which was barbecue and then we brought in pitch-in for the rest of it. And they had Cornhole games setup and the children had fun. And Barb enjoyed it and we walked over and that was fun for her, so.

[00:45:23]

JT: Right. Thank you very much.

[End of Interview]