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Julia Bell interview for the Lest We Forget Collection of Oral Histories

Julia Bell

Judy Leasure

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Julia Bell

WRIGHT STATE
JULIA #28 & 29

**WRIGHT STATE
JULIA
TAPE 28**

QUESTION:

O.k. Julia can you, uh, go back and first tell us... tell us all your children and then focus in with Chuckie or Chuck now and tell us, umm, about maybe from the time he was born and lead us up through some of his early years.

JULIA:

O.k. I have 3 children, uh, Chuck is the middle child, uh, his... he has an older sister and a younger brother. Uh, his brother was instrumental in helping with Chuck during the early years. Umm, my first clear memory of Chuck was when I came home from the hospital in 1970. When I, uh, came home... well, my illness as a result of being very ill I lost my memory. So, when I came home I had no idea of what it was like, umm, well... I didn't even... I had no idea what the world was like... my environment all of that... all that was new to me. When I saw Chuck what impressed me the most was his activity. He was extremely active. And, I would watch the other children and there was so much difference between them. Chuck would come to me and he'd stick his hands in my face, umm, he would, you know, when he was moving around he would literally destroy everything that was around him. And, he thought it was fun. To him all of this was fun. When I asked about Chuck I didn't get, you know, very many answers in the beginning and that first year... that first year was a struggle and it wasn't Chuck's fault or the families fault I was just trying to find my way in a world that I didn't understand. When I... I got pregnant that first year and when my baby was born I considered Chuck and his brother and sister, I considered them my husbands children and I considered my

baby, my baby. She became ill at 3 weeks we took her to the hospital and, umm, when the doctor came out he asked about our children. And, all of his questions were directed to my husband and I would interject and at the time, umm, he said that if she lived she would be severely retarded. Uh, she had lost, uh, oxygen to the brain for a quite a bit of time and he said she would be severely retarded if she lived. I'm thinking that my baby, you know, I can take care of her. I had taken care of his children and he had a retarded child and I was taking care of him and so I'm telling all this to the doctor not realizing that he's looking at me and understanding that there's something that's not quite right. And, so he starts asking me questions about do I have help and, umm, how old the other children were and I'm telling... oh, no I don't need any help any more because I'm doing well, I can take care of the children. And Chuckie's a little bit slow but I'm doing good with him. And, the doctor looked at me and he said, raising one severely retarded child would be difficult, raising two would be impossible. And, he went back into the room. Umm, I don't know how much time passed before another doctor came out and told us that she had passed. At her funeral one of my husband's friends came to me and said he was sorry that I'd lost my baby and then he nodded over at Chuck and he said it's a shame that she died and he's still here. I didn't understand what that meant and so I said, what's him being here got to do with her dieing. And, he said, well, it's just a shame that your baby died and the retarded kid is still here. That's when I knew there was something wrong with being mentally handicapped. Umm, and I said, my baby would have been mentally retarded too. And, then he said, well God knows best. And, I'm thinking God knows best why would he give her to me if he's going to take her away, you know. What is this about mental retardation that they're not good enough?

They're... they're not as good as regular people and in the hospital I had my own issues there and it was the normals versus the mentals. And, so on the outside what I related that to was it's the normals versus people with mental retardation. This world is built for normal people. It's not built for people who are mentally retarded. It's not built for their families either. Umm, I used to go to my daughters grave every day cause some of the issues I have... If... if I don't do things repeatedly I tend to forget especially way back then it was more of an issue then. So, I would go to her grave every day and I'd go early because if I went at a time when there was traffic I could get thrown off and I had to focus on a certain path and when the streets were empty it was easier for me to do that. One day I... I don't know... looking back I think what happened was that I, uh, I must have left too early and when I got to the cemetery the gates were locked so I couldn't go to her grave. And I had a flashback of... I think they were registered nurses who had come to the home when Chuckie was small and they said that... well, I don't know whether they said it or there was another person who tried to tell me that keeping Chuck would ruin my family's life. And, so apparently they told her and she was the one that told me that all I had to do to spare everybody was just leave the house leave him there and when I got back he'd be gone and everything that reminded me of him would be gone.

QUESTION:

What did they mean by that? We're they going to take him to an institution.

JULIA:

I believe so because... they were going to take him to an institution. Umm, what I was told that the decision not to institutionalize him was mine and it was mine against

everybody's who... everybody else's opinion that it would be best for all concerned. If, umm, if we institutionalized him and I ...

QUESTION:

How old was he when they told you that?

JULIA:

I wasn't... I didn't really get that in the conversation. But, I'm thinking he was something like 3 months and I... I... I'm judging that he was about 3 months old when that statement was made because at the time when he was born... they said that his forehead... the... the features of mental ret.... of Down Syndrome... he's downs. And, the features of Down Syndrome, umm, were noticeable but when you looked at my husband some of those features looked similar to just the way he was built and his hairline. So, it wasn't until, uh, he was 3 months old and I guess we must have taken him in for something and they made the definite diagnosis that he was downs. And, nothing could be done for him. He would be a vegetable. The best thing to do was institutionalize him and forget he was ever born. Umm, I don't remember the arguments but apparently there were. Umm, well I don't... I won't say that they were arguments I would say they were discussions as to what was the best for the family. And, I must not have cared about the family I must have gone against everybody and chose to keep him. And, my husband just went along with my decision. No one let me forget that it was my fault when the family started unraveling. Umm, I was always threatened. Well, I won't say always cause I don't really remember all of it but I do know at certain occasions I was threatened that CSB was going to come and take the children from me. So, I isolated my _____ (INAUDIBLE) and I isolated them... Outside of letting the

kids have company I didn't let very many people in the house. I went out to things that had something to do with mental retardation. See at the same time all this was going on I'm trying to relearn the world. And, what I learned was that people like me and Chuck didn't belong. And, I thought of, you know, when things unraveled and my husband decided on, you know, he needed a life, umm, I thought he'd take Bev... Kevin with him and they could have a good life and somehow I would figure out... I would figure out how Chuckie and I were going to survive. But, when he left he left all the kids. And, the kids helped me. They helped me understand and they would tell me, umm, not to talk too much in public and just come back home when I came home I'd talk to them and then they would explain to me what was meant by some of the conversations. I had a habit of calling people normals and they told me... now... now don't talk about the normals, you know, you just tell us about them when you get home. Umm, it was difficult taking Chuck out. Uh, one time we took him downtown... well... I... I... it wasn't one time; I took him downtown a lot. And, I... you know, I had the other kids with me and what I would do was I'd let them get on first and they could run to the back of the bus and then Chuckie and I would sit up front. Umm, part of it was because, you know, Chuckie was active and he would do things and people would look at us. And, I didn't want them to be embarrassed. Umm, one time we were downtown and we were at, umm, it used to be... I think it used to be Winters, uh, it's Kettering Towers now but we were upstairs, uh, and we went to come down on the escalators and as we were... no, I had taken the kids and I said stand back so, you know, because we were holding up everybody and so I had them stand back and Chuckie was pulling away because he wanted to get on the escalators. And, from down in the lobby I heard this (COUGHING,

(THROAT CLEARING) I looked down and, uh, everybody looked down to this and when I looked down she was staring at Chuck. Beverly and Kevin just lowered their heads and looked at the ground. Then there was this man he stopped everybody and he said ma'am, you get on we can wait. So, I got on and we got down... down to the bottom and she was, you know, like she was disgusted. And, so I told Bev and Chuck to go to I think it was Frisch's down there at that time and get a booth for us to have lunch. And, me and Chuckie we were going to teach her a lesson and me and Chuckie went back up on the escalators and by this time everybody's watching us and, uh,....

RESTART

Umm, we went back up the escalator and when we got to the top another man stopped and he let us on and this time I braced Chuckie and then I stood on the side of him and when she stated that (LOUD COUGHING) again I lifted up Chuckie's hand and we waved to her. And, she started stumbling as if she was drunk; I guess we caught her off guard. And, she started stumbling and it just made me feel good... it just made me feel good, it just made me feel that, yeah, we might not be what is expected out here. We might not be normal but then normals not so great sometimes. And, then Bev and Chuck they didn't go to Frisch's right when I told them to. But, when they saw her stumble they clapped and then they ran out the door. And, then I got off and then everybody was smiling. And a young man came up to me and he said, way to go sister you and your little fella made my day. And, I think that as much as I was hurting because we weren't normal, we didn't belong there, you know, when everybody was smiling it was like, that's o.k., you're o.k. You know, it was as if they realized we weren't the problem. And, I just felt good and we went and we had lunch and the kids

never mentioned it ever again. They never mentioned it ever again.

QUESTION:

Did you ever during those early times did you have support services or did you have a family... or a church... did you go to church? Was there support or was there programs or something like there are now. What was there to help you?

JULIA:

In those early years there wasn't anything, uh, part of it was because I'm playing this role. Uh, when I got out of the hospital, umm, it was on the basis that I remembered my family. You know, umm, the doctor thought I was playing a game because I wanted to be mentally retarded like Chuckie. And, that I was just playing a game for my husband's attention. And, so he said if the other staff found out that I didn't remember..., because what... what had happened was he asked how Julia was and at that time I didn't know who Julia was and I had a flashback of a young lady with 3 small children. And, I thought that she had come to visit me and she had gone home and I didn't remember her visit. So, from the flashback I made up this story that she went home to be with her family... with her children. And then he said, well who are you? At that moment that's when I realized, you know, who am I? And... and I was angry at myself because I hadn't made up a name for myself and so when I went home I had to live with that. Umm, the pretense that I started in the hospital was taking things that my husband said and feeding those to the doctor. And, so when I went home I had to keep up that pretense. So, I... my mother and my family, I just kept my distance. I didn't know what to tell them. And, and I'm not sure how they saw Chuck and my decision to keep him. I knew my husbands family. I knew what they thought

but, umm, I also had heard that my family said it didn't come from their side and his family said it didn't come from their side. So, I just felt that I couldn't talk to anybody.

Umm...

QUESTION:

You were trying to place blame? Is that what it was?

JULIA:

I... It's my thought that people... nobody wanted to acknowledge that this could happen in their family and so they were both looking back and saying, no, didn't come from our side. Umm, and I think from what I saw in society at that time was that the stigma didn't stay with just the mentally handicapped person, it was with the entire family.

And, so neither family wanted it to be because of them. That's... that's what I believe. I don't know cause I... I never really sat down to ask my family about it. I just played the role and I kept playing the role and I did end up going to church, in fact, my saving grace was when I started going to church, But, then again, there were a lot of churches that I couldn't take him to. I was welcome but he wasn't. And, if he can't come neither can I. Umm, there was one church, umm, that's said he was welcome but they would have to discipline him. And, to, umm, get him to be like the others. He wasn't like the others. No amount of discipline is going to make him like anybody else.

So, umm, I just moved from church to church until I found one that was accepting of him. Umm, I tried to get involved, umm, partly because, actually it was mainly because the more that I learned how to deal with the world the better I was able to function at home. The more I could take off of the kids because they were... they were a tremendous help to me, especially my son, Kevin. He's a year younger than, no he's,

two years younger than Chuck. But, from the time he as just a little... little..., little guy he was the one... he was the one who was sort of the anchor, you know, I couldn't figure out things and he would sit down with me and sometimes he would get frustrated and say mom I can't make it any clearer for you, you're gonna have to just trust me on this one. Umm, he would take Chuck, uh, if I, you know, there was a time when I dressed Chuckie in a, I don't know, it was a little character outfit and.., oh, no, he can't go out like that. Umm, another time I... well, actually it was the last time I did it, I was taking him out and Bev got in the door, NO... NO... you can't do that to him. And, then she called, Kevin... Kevin come look and she what mom's done to Chuck. I mean it was a nice little outfit, but it was a character and they said he was too old for that, he was about 12 at the time and they said he was too old for that. so, that was the last time I did the little character things with him. But, we would go, uh, wherever I'd go I'd have all the kids with me and, uh, it was hard on them... it was hard on the others. Umm, we... when... oh, I guess Chuck... oh, I guess he was about 4, no he was about 5 I guess, when we moved to a new neighborhood. I'm sort of jumping around here. We moved to a new neighborhood and my daughter she had, you know, a little friend and I'm thinking, oh... the first little friend in the neighborhood. And, one day I heard this screeching from the garage and I raced to the door and it was a little girl... GET HIM AWAY FROM ME.... GET HIM AWAY FROM ME... GET HIM AWAY FROM ME... and I was trying to say... oh, what am I going to say? How am I going to handle this? What am I going to say to her? And, I was standing in the screen looking out trying to think of... o.k. I need the right words to say to this child and Beverly walked up to Chuck and said, he's my brother and we love him and if you can't love him too you'll

have to go home. And, the little girl..., she just sort of sheepishly went over tapped him and, uh, after that the little kids they accepted him. Umm, in fact they did this little game where they tried to get his attention and whoever got his attention would get a little extra point. And, uh, there was another part to it... I don't know if it was holding his attention the longest or whatever but it had... they involved him in this little game. And, uh, it didn't last long because Chuck didn't stay there that long. And, it was just a little thing for them to do and then Chuckie was on his way and then they'd go on with their regular game. And, you know, I don't know... I've never asked the kids about why they did that but I'm thinking that it just made them like other families, other kids. You know, they could play their little game and Chuckie was a part just for a little while... just for a little while.

QUESTION:

What made you make the decision when there was obviously so much pressure for him to be sent to an institution... what was it that guided you to fight so hard to keep him at home?

JULIA:

The reason that I fought so hard to keep Chuckie at home was because I know what it's like when family leaves. Although I don't remember family... now there's a part of me that's missing that. And although I know my family now and I know other people now that void is still there. Umm, I thought... I thought it would go away, it never did. But, back then... back then the memory of the hospital... there were times... now, I can't really blame the nurses, but then I did. Umm, it was the normals world. You... you had to do what the normals said. Umm, you had to behave, umm, and behaving meant

doing what the normals said. One time, uh, I was just learning to walk again and they had gotten me to... to the chair and, umm, I got finished eating and I was tired of sitting in the chair so I wanted to go back to bed and I... they said just push this and we'll come and get you. Well, in my estimation they didn't come like they said they were. Now, I don't know whether my timing was off... I don't know why but I know they didn't come when I pressed the button and I pressed it again and they didn't come. So, I decided that I could get back to bed by myself. And, I just replayed in my mind what it took to get me to the chair minus having people on either side when I would sort of lean too far and they would help steady me. Umm, I almost made it back to the bed. Well, actually I did make it back but the bed wasn't lowered so I tried to jump in it, I fell. Umm, for that I got tied to a chair anytime I was let out of bed. Umm, when my husband came... if anybody came in the room it was as if they liked me, but when he wasn't there that's not how it was. And, I didn't want... I... I... there's no way I would subject Chuck to that kind of... and, although I didn't know what an institution was, I heard the word. Just hearing the word made me think it was a terrible place. It was worse than a hospital. And, he wasn't going there. He would be locked away. He wasn't going to be locked away. I know what it means not to be normal. Nobody... nobody's going to hurt my child because he's not normal. I don't care how not normal we are we are human beings, we need to be treated as human beings and this world did not do that for us. And, I carry those scars. I try to get along in this world but I notice... I notice now even when I talk every once in a while I'll refer back to years earlier and the person that I'm talking to doesn't understand that sometimes. I'm not really talking about an incident or a person that's right here and now but they say something and I flashback. Chuckie's

flashbacks whatever they... they be I want them to be good. And, if there's nobody in them but me and him that's o.k. You know, I saw it as me and him against the world. I... I ruined a lot of lives because I kept him. It's not his fault he was born mentally retarded. I don't know what happened... well, I do have flashbacks of what happened to me. Again, it's not anybody's fault it's just something that happened. And, it's something that I have to live with just as Chuck lives with his mental retardation. But, it doesn't have to be as ugly as people make it. My husband did go on and I'm assuming he has a good life now. Sometimes people want to blame him for leaving but unless you walked in his shoes you don't know... you've got no right. Umm, he had a beautiful family. He went a long with me to keep Chuck. And, then I got sick and instead of 3 children with someone to help him he's got 4 kids. And, my understanding of the world in those first years was... it... it was hard... it was hard on everybody. Umm, and you know, we kept people out so no one would see. Uh, when people came, uh, I could tell that I was... when I was doing something wrong because he would move close to me. And, he'd hold my hand or touch in a way that I knew just be quiet... just be quiet. Umm, he loved Chuck... he loved Chuck. But, when other people were around I could see the pain in his eyes. Especially, some who... they didn't really make fun of Chuck, but there was this one person who wanted Chuck to drink beer... make a man out of him. No, he's not going to do that. You know, he might not be normal like your kids but he's not going to be a drunk either. You're not going to make fun of him. He's not a toy for you to play with. He's not going to be the object of your fun. So, there are circles that don't think much of me. That's o.k.

QUESTION:

What happened when it was time for Chuck to... when he became school age... when it was time for him to go to school?

JULIA:

When Chuck became school age... well, actually..., now, this happened before my memory loss. They had a program called Early Intervention. Chuck was one of the children chosen to be in that program. When I came home from the hospital my husband told me about, umm, the kids going to school and then Chuck... there was a special program that Chuck was in. Well, actually Beverly was going to school. Chuckie was in a special program and Kevin would be home with me because he was... he was about, lets see about two... two back then... two maybe three... no, I think he was two then. And, uh, so he was in this special program. It was in the basement of I think, South Park Methodist... it was a church... in the basement of a church. And, then when he graduated from that program he went to the basement of another church. Umm, school really helped him. Umm, they had to teach him how to crawl again. Uh, he learned to walk before learning to crawl so they had to teach him how to crawl again. I'm... I'm not sure of how that worked but that's... but, uh, school was good for him. Umm, he got sick and I was afraid that the teachers would report me to CSB. I'd been threatened with CSB so much that I thought that anything that I did wrong CSB was going to come and take the kids...

TAPE END

The teachers could.., they'd be able to see that he had slipped backwards. So, I kept him home from school and one of the teachers called and I said he slept during the day so much, which was true because he was up at night and he'd sleep during the day.

And, they said, just send him. Umm, we'll work with him when he's awake. And, I debated whether to send him and chance them calling CSB but then I figured if I didn't they might call CSB and CSB come to the house. And, that might be a worse thing. So, I sent him and, uh, there wasn't a problem. Umm, umm, there was an exclusion from regular school. Umm, but by him coming in through the Early Intervention I really didn't have to deal with that much. I had to go to schools, umm, when I... eval... when... for his evaluations. He always did poorly on his evaluations. And, uh, the psychologist would always ask have you ever thought about institutionalizing him? And, oh I think when he was about maybe 9. One of the psychologists said, you know we have homes in the community now, have you thought about that? And, umm, I hadn't. And, when he was about 12 I tried it for a weekend. Just to get a break, And, uh, it was Resident Home Association. And, it worked for that weekend. But, I think the... the people at Resident Home I think and in fact I'm pretty sure they were much higher functioning than Chuck. But, even at that time I... it was a home and I had no, umm, no problems with the home. I...I liked it. I liked everything about it. But, without Chuck, I mean, Chuck (DOOR BELL RING) he was just part of me, you know. So, umm...

RESTART

When he was about 12 we went to Resident Home for a visit... for a weekend so I could get a little bit of rest and that worked out well. Umm, I got... I got to have that break and it... he... he enjoyed it, you know. He was, umm, you know, it was a place where he was accepted but I... long term I couldn't... I couldn't let go of him. Umm, at... and at that time, uh, Resident Home Association the people in that home were much higher... much higher functioning than Chuck. But, that was the first glimmer of hope that he

could go to a home and be treated as a human being. Umm, I had never been to the institution but I had heard people talk about them. And, from what I heard I... I didn't even want to go there. I mean there was no point in me going, I knew it just was not an option for me. Umm, I thought Chuck would be with me all his life, umm, but as he got older and our schedules... we had to have a schedule, somebody had to be home. And, uh, when it got to the point where the kids were growing up and they were going to be leaving home I realized, actually I... I ended up being sick and being in the hospital and realizing what's going to happen when the kids are gone and it's just you and Chuck. You know, how are you going to manage? How are you going to get home? There was just so much that I hadn't thought of. And, by this time, uh, we were settled in a church that even had a church school for Chuck. It was called the Church of Special Love. And, uh, one of the people there, umm. worked at MDC, Montgomery Developmental Center and, uh, it was new at the time and she said Julia it's a beautiful place. I'm going to be there, I'll be able to look in on him every day. And, with her urging, umm, well actually everybody was urging but she made it not only... not only practical and what would be best for everyone at this point and time in... in our lives. But, also she gave it a human touch where I wasn't sending him away because of anything he did or, uh, because something was wrong with him. It was... this is a good choice for everybody so that everybody can continue to grow. And, I accepted that. However, there were more things to come. Umm, the deinstitutionalization meant that Chuck had to leave there because MDC, uh, was for people who were, I think they said, the Barbara C Law which meant that a person had to come from an institution. They got priority. Chuck had come from home so he was one of the ones who had to

leave MDC. And, uh, so I was ready to bring him back home and they said they had a plan and that was they were going to put them all Chuckie and... and there were 26. They would go to the special unit. Actually the special unit was the 3rd floor of building 61 at Dayton Mental Center. And, it had been closed the year before because it was so deteriorated. And, uh, there had been abuse of the clients who were there. Uh, another parent was telling me all of this and so I'm thinking Chuck's coming home he's not going there. And, the parents got together and, umm, it was to fight the Ohio Department of MRDD. And, one of the parents who was there talked to me about staying with the group because there was strength in numbers. And, I have... I have a gift where I... I do write and she was reading something that I had written and she said, Julia write for all of our kids. Let people know that our children have names. They have personalities. They have feelings. Let people know that. So, I stayed with the group and Chuck went to the special unit. And, I'd show up any time. We were supposed to let them know when we were coming. Well, I worked right down the street and no, I'm not going to let you know... I'm gonna show up. You'll know when I get there. And, there were times when I'd get there and everybody was gone. And, then one of them... one of the attendants said, well Ms. Bell you know that's... that's what happens when you don't call. And, I said, well that's fine. You know, I'll go but I'll be back. When I come back I expect that Chuckie's being treated well. And, at the special unit... it was... it was good... it was good. Umm, they remodeled that 3rd floor which was the best floor in the building. They remodeled it and things... things really... they did do well for our children. Umm, but when it was time for them to go and they would place them in homes in the community. People in the community didn't want them in... they

didn't want them in their neighborhoods. And, when the... the home that Chuck was going to was a home that had been a children's home. Well, Chuckie was no longer a child. And, I don't know how it got out but I heard that there was this adult moving into this home, this adult man that was moving into this home and they were... I don't know whether they were going to burn the home down... it... I know they were going to do something... I think it was burn the home. That... at least that was the rumor that I heard. And, also that if he stepped on their property they were going to shoot him. And, I talked to the supervisor and they said, Ms. Bell don't worry we're going to take him in the van we'll bring him home. Don't you worry, you don't have to come. And, I'm not sure whether I rode in the van there I think I might have. I... I'm not sure about him going there I do know that I went home I got in the car. I got a baseball bat and I parked up the street. And, I said anybody that comes after my child... I was going to go to jail cause I was going to do my best to use that baseball bat. They were not going to hurt my child. They were not going to hurt my child. He hadn't done anything to them. He just moved into a home. That's all he did, moved into a home. And, they didn't think he was worth living. I woke up some time in the morning. Nobody had bothered him. I didn't see anybody. Umm, baseball bat, you know, I went to sleep... baseball bat in my hand. I drove home. Part of me said they're all talk; they're not going bother him. But the other part of thought what if they do and your not there. You're living your life and somebody hurts him. You know, you would have failed him just like you failed the rest of your family. But, in time... in time I realized it was going to be o.k. And, umm, one day I went and I was at the home and a neighbor was out and I just went over there and I said, you know, I want to meet the people living my child. And, uh, I don't know

whether it made a difference but I know I... I was able to have some piece because... he seemed startled at first but it almost seemed as if he ended up with some recognition that, yeah, this is somebody's child. He's not an it. He's not whatever normal people think he is or thought he was. Because times have changed... times have changed. But, back then...

END OF TAPE

TAPE #29

QUESTION:

What life's like for Chuck today and what life's like for your family and you know, what how maybe the world is different. How do you see the world being different?

JULIA:

With the changing of times, umm, it's... it's just like day and night now. Chuckie is... he's... actually he's in the same residential home but now everyone in there... I think everyone's adult... and adult now. Uh, there's... there are groups that go in and spend time with them. They are working. Well, Chuck is at, uh, he's at an adult activity center. They have jobs. Umm, my greatest hopes for Chuck to be able to work in the community and staff both at the... the activity center and at home, uh, tried him on several different jobs in the community. And, I've come to accept that, umm, Chuckie will not do community. He won't... he will not do community employment. Umm, his skill level isn't that high but he's good at what he does. And, he has a little job in, you know, at the center. And, he's, you know, there are certain jobs that he likes better than others. Umm, and he's a tremendous help at the home. He understands well. Umm,

you know, there are some things that, you know, he knows that you're asking him to do something... sometimes he's not quite sure but he... he goes and he does what he thinks it is your asking. You know, there are things that he understands extremely well. There are things that he has a routine that he does. There are things that he does somewhere and when he comes home he does those same things. Like, taking out the trash, umm, you know, cleaning up. There's a lot that the he... he just... just likes to do. And, it's not this hopeless vegetable. His, sister and brother they have very good jobs. Umm, they are, you know, very good in what they do. They have their own stories to tell. And, I will let them tell their stories. But, they, umm, I can say that in both... in both of them they have that human touch. You know, helping others in their jobs... there... that's what they do. They, you know, one's.... one's a principal and ones and EEO specialist. But, they help others. And I...and I know they have scars too. I know they have scars. But they didn't let those scars stop them from being the best that they could be. And, uh, I've worked 19 years at the same place and, you know, after 19 years... and I look back, uh, to the parting words of the doctor. You'll spend the rest of your life on mental wards or in institutions if you don't talk about your problems. And, I've spent my life hiding my problems and, uh, no, didn't have to be where he thought I was gonna be. Umm, and Chucks... Chuckie has been a big part of that. Focusing on what was best for him. Umm, did I do it to the point of hurting my other children? In all honesty, I probably did. Umm, I would like to say that it worked out for all of us and it was the best for all of us. But to be honest, no matter what decision you make whether institutionalization or staying at home it's not going to be best for everyone. Somebody will be hurt. The more support that there are the less damage that there will be. The

more supports that there are the more of a family you can be. The more positive your relationships with one another. The more supports that there are the healthier your family will be. Without those supports somebody is going to be hurt. And, it's likely that everybody's going to be hurt, it's just to what degree.

QUESTION:

And, that's what you faced during the 70's and all that was _____ of lack of support?

JULIA:

Yes, and you carry the scars. You carry the scars. They just don't hurt as much but you carry the scars. Umm, without my faith I don't know that I wouldn't be a bitter person. Because the scars are there. And, I find myself talking sometimes... I'm here... I'm today... I'm... everything's o.k. But, I can slip and I can talk about something that happened back 20 years ago and if you didn't know you would think I would be talking about something that was going on with somebody who I'm dealing with today and that's... that's not the case. Just for some reason something was said the scar didn't open up and I wasn't bleeding again but it touched on where that scar was and I started talking about it. And, I can talk about it without the anger. It's... you know, like sometimes I'm talking to someone and I'll be talking and I... I don't know whether it's really true that I'm talking without anger. I think I am, but I might not be and I'm feeling that loneliness that I felt back then. Even though in today's world I'm... I'm surrounded with people. I'm busy. I've got a lot that I do. Things are going well. But, when I am lonely it's the loneliness of 20 years ago. 30 years ago creeping back.

QUESTION:

Is the fear gone? Is it gone for Chuck and for you?

JULIA:

No the fear... the fear that I had then it's still here..., it's still with me today. Because things can change. Umm, funding. And, although there are supports there not enough. And, when it comes to cutting, whose going to be cut. I don't want it to be Chuck, but at the same time knowing what I've gone through I don't want it to be anybody else's child either. And, if we... if the fear isn't there we could become complacent and before we know it, it's the 60's and the 70's all over again. That's my biggest fear is that we can relive the 60's and the 70's and they'll be rationalizations about why we have to do this. And, basically what it is, is you're going to take money and you're going to use it for something else. It's the same old story, the normals world. We're going to do what's best for the normal people. That's my biggest fear is that what has been gained will be lost and that's why this project is so important. It is so important that people don't forget. You know, and... and like the young families they don't know. They... they haven't had to deal with it. They don't know. And, as the older ones die off without this there stories will be lost. What happened before can happen again if we don't stay vigilant it can happen again. We can't forget. We can't forget. Because if we do we're opening the door to let it happen again.

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