

5-1-2004

# Mark Gerhardstein interview for the Lest We Forget Collection of Oral Histories

Mark Gerhardstein

Judy Leasure

Follow this and additional works at: [https://corescholar.libraries.wright.edu/special\\_ms396](https://corescholar.libraries.wright.edu/special_ms396)



Part of the [Oral History Commons](#), [Social History Commons](#), and the [United States History Commons](#)

---

## Repository Citation

Gerhardstein, M., & Leasure, J. (2004). Mark Gerhardstein interview for the Lest We Forget Collection of Oral Histories. .  
[https://corescholar.libraries.wright.edu/special\\_ms396/17](https://corescholar.libraries.wright.edu/special_ms396/17)

This Interview is brought to you for free and open access by the Special Collections and Archives at CORE Scholar. It has been accepted for inclusion in Lest We Forget (MS-396) by an authorized administrator of CORE Scholar. For more information, please contact [corescholar@www.libraries.wright.edu](mailto:corescholar@www.libraries.wright.edu), [library-corescholar@wright.edu](mailto:library-corescholar@wright.edu).

*Mark Gerhardtstein*

WRIGHT STATE  
MARK #30

**WRIGHT STATE  
MARK  
TAPE #30**

**MARK:**

Well in the 50's and 60's, uh, and certainly earlier than that, uh, families did not have the same opportunities to have their children educated \_\_\_\_\_ (INAUDIBLE) the other children that we now see. We take some of this inclusion, uh, for granted, uh, as children are...

**RESTART**

Well in the 50's and 60's and certainly before that families who had people with substantial disabilities, umm, were excluded from public education and they were done so in dramatic terms. They received the letter which we now refer to in terms of the form number as the E-1 Exclusion Letter. And, there were so many families that got it they had a form for it and it basically said that your child by name would not benefit from a public education with other children and was therefore excluded from coming to the public schools to receive that. Even though you're paying the same property tax and school district support that anybody else is. That had to be one of the most hurtful and, uh, hard to recover from. Uh, discriminatory practices and feelings, experiences that families experienced between all the things that happened when their children are young between doctors, educators and professionals. That had to be one of the hardest ones, the most hurtful. Umm, as time progressed, uh, what happened then was those same families gathered together in church basements and in other places and created their own educational system outside of the, uh; format, uh, of the public schools. And, uh, created through the structure of their own making, uh, schools that

they began even to pay teachers to participate in and that's where the Council for Retarded Children at the time started. And, the parent advocacy efforts really started because of their very, uh, discriminatory practices that were, uh, took place against their children and against them in public places. Uh, so at that point then, uh, you saw segregated schools being created by families to help address their... their children's needs. And, from that you saw them helping to create County Boards of Mental Retardation through legislation who without being able to change the practice of the public schools at the time created formalized schools that were segregated in nature for children with severe disabilities. And, by way of example in Montgomery County when I first came to the county board almost 25 years ago there were 3 schools that were organized for children with disabilities that were totally segregated and run by the Board of Mental Retardation. We served over 400 children in segregated schools. And, those schools were run as well as one could run them and as professionally as one can run then, however, they were segregated. Uh, and my experience is that separate but equal didn't work for anybody else. Uh, and they weren't equal even though they were separate. And, uh, it kept children with disabilities from having the experience and the challenge of being in an integrated environment and almost more than that. Uh, it kept children who did not have disabilities from experiencing the diversity of the culture that they were born into by being separated from it forcefully. They didn't know children like this existed. So, all they were left with was the prospect of being afraid of what they didn't understand. So, they'd go into Meyers and see a child they'd never met before and because of their disabilities they'd be afraid of them. And, if had they grown up with them they wouldn't have been afraid. Uh, so as we progressed then into the 80's and so on, uh, people began, uh, through legal means and other more enlightened public practices challenged the wisdom of segregating children with severe disabilities. And, in this county I'd say in

the 80's and in the 90's we moved aggressively to completely eliminate educating children outside of their being with other children. So, now in 2004, uh, there are no children in Montgomery who have severe disabilities who are educated apart from other children. And, now the Board of Mental Retardation does offer some educational services in the preschool area and some small amount in the school age program. But, there... it's entirely in the public education system, uh, because children should be educated with other children.

**QUESTION:**

What was the struggle, uh, in specifically with the term mainstreaming and that was of that concept and how frightening that was? What was that struggle like for mainstreaming?

**MARK:**

Well, mainstreaming, umm, was a concept that, uh, proposed that children should be educated with other children. And, in some ways the public schools who were receiving children, uh, from these segregated schools needed supports so some of the struggle was how do we integrate these children without having any education for our staff, any resources or any space within the building to properly accommodate them? So, just like any other expansion had to happen because you had new neighborhoods. This had to be planned for. And, in the communities that did this well you didn't just close schools you worked with school districts to help them integrate children. Uh, because you needed to propose ways for other children to be educated about how to be with people who had differences, who for all their lives had been kept apart from them. So, concepts like bus buddies and lunch room buddies and gym buddies, uh, were created so that people even though in... in every classroom children weren't all totally integrated. They became part of the culture of their school and they did that by being known by name. Uh, my own

children were in a school where one of the classes that were re-integrated was moved and they could tell me without my ever asking them what the names of every child in that class were. Because they were different and you noticed it. And, they knew something about them that was humane, something that endeared them to them rather than something that scared them because they walked in from the bus. They'd know how he walked in and what kind of challenge he had getting into the building. They'd know what challenges they might have communicating or how they'd be different in a gym class and what their limitations might be. And, it grew a sense of compassion, uh, without pity. Uh, pity is misinformed and misplaced. Uh, and it causes people to act in condescending ways when, uh, compassion is informed and enlighten based on knowledge of an individual person by name. So we saw compassion growing in a whole generation of children who were growing up with people who are more like them than unlike them in that we're all human beings first and second we have differences that we all have to understand and address.

**QUESTION:**

I remember those days we worked together... I remember the... part of the... most difficult part probably was working with families and working with staff and the fear that kept families from accepting the concept of mainstreaming. Can you just address that?

**MARK:**

Well, there was a lot of fear that, uh, from the, uh, side of the... of the experience where the families who were going to have to move their children, uh, came from and from the staff who were caring for them all these years and the best way I ever had it put to me was when I got up in front of a group of staff and was proposing that we were going to do this and this was the right thing to do, meaning children should be educated with other children. People should be a part of their community, not apart from it. People should be

able to work in the community in to which they were born. People should be able to live in the community in to which they were born, inclusion not segregation. Those concepts everybody goes, yeah, yeah, yeah, but now it's my job. Now it's... now it's taking a risk in my life about that. And, from the staff point of view we have the state championship basketball team. I mean, we were good at what we did to create... to do segregated schools. We had people who, uh, who did the best they could do in segregated environments. We had great music programs, great art programs, great other things. Uh, and the question was, but isn't it better to be on the top of this pile then to be on the bottom of that one? I mean, that's a bluntly as I can put it and as bluntly as it was put to me. And, I think that... that's where we had to have some faith that people would grow more, uh, by being... by having the opportunity to see how everybody else's is living and performing in the school environment then we could ever perform. Uh, have them learn when everybody around them had significant social and other mental disabilities. Uh, my own experiences unfortunately that... over the years we've created more mental retardation than we've ever helped because some of our situations... our settings helped us to limit people by our own limiting expectations more than we were able to help them. We didn't have a context to see what normal was so we accepted more mental retardation than we ever should have. We didn't push back enough. Uh, there was too much pity, if you will. So, those people were afraid of the move from a staff point of view and some of those staff came back to me years later because they were very employable in the public schools and said it was the best decision we ever made because they matured in their teaching careers along with the students. Families on the other hand, uh, said, o.k. this sounds like an o.k. thing to do but, you know, these are the same people that threw me out 3 years earlier now, you know. What is it about this that makes this different than when I got the letter 3 years ago? I... and we said because we're working

with them to support you. And, what we had to say to families that we couldn't... we didn't anticipate originally and I had one quick meeting where I saw this was necessary, was we had to say to those families, you know and if it doesn't work out, Ma'am, for you and your son you can come back. Uh, and we made sure that we helped it work for those families because there's no reason why it couldn't work. But, when you give somebody a lifeline into a possibility but you don't give them a line back they will be afraid to take the risk. Because you're... you've taken away their security if it doesn't work. And, what we... we had nobody come back. Although, we had conversations with school districts about things that weren't working and when out and helped them improve those situations. Uh, the other thing we did that caused this actually to take almost 10 to 15 years to accomplish. We didn't just say, tomorrow we're closing four schools. The first thing that we did was we... we changed how we took children into, uh, schools. We said, if you have these social capabilities and these intellectual capabilities you can no longer be admitted to the Board of Mental Retardation. So, public schools started growing in their numbers because we weren't accepting the segregation of children, uh, in the same way we did before. And that mostly happened coming out of preschool and, uh, being referred when people moved into the community. Uh, now some of those we made exceptions to. But, for the most part it started happening by attrition. Graduating classes would go out, fewer children if any would come in from below and then we took children from within and said, who are the people who are most likely to succeed and we looked around at each other and said, the people with the greatest social skills will succeed first before the people with the least social skills. (COUGH) So, we offered the people who had the greatest social skills the opportunity to move first and wanting to build on their success. So what happened, those people then were very successful and we helped them to succeed and the schools helped them to succeed. This was not us against the schools. By this time the

schools knew this was the right thing to do. Uh, but they wanted our help and our support and we helped them design how people could be transported, where all the people lived, how school districts could coordinate to create primary, secondary and middle school levels. How it would make sense in the North, how it would make sense in the South. Umm, what kind of teachers... we offered the teachers who were leaving us because we wouldn't have classrooms. Uh, direct access to public schools who might be creating units and many of them are hired. So, they felt like they had the support of professional resources, planning and professionals who knew the consumers to begin with. Families, umm, did lose touch with the Board of Mental Retardation quite a bit during those years. One of the assurances we gave families and we gave school districts is while we are not going to provide school services, uh, we are going to reinvest funds that would have gone there into adult programs and into the residential needs of people with mental retardation because as people are aging their children are aging with them and now we have, you know, people 80 with 60 year old sons and daughters living with them that need residential services. So, we've done that and now many of these children are coming back to us, Uh, it's an interesting scenario at this point because people who've come up through our system in the... 2004 as I come back to the Board of Mental Retardation after being away for a while, uh, are coming back and saying, in some cases you have the people who have been here all these years and came up through our segregated schools and through the adult services and they're saying this is what I want, I'm very comfortable with this. What you offer in the adult programs is what I'm looking for and I don't want anything changed, in fact, I'm afraid of anything else because it would mean another risk for me after being excluded all these years. On the other hand, people who've come up through the education system, uh, where they've never been segregated, never... even their early childhood experience with us is integrated. Has said, Mark I've never been

segregated in my whole life. Why would I want to do that for the first time when I'm an adult? I'd like to find resources and options in the community not apart from it as an adult. If it was o.k. for me to do that as a child why isn't it o.k. for me to have that same model of integration? Model of being a part of the community as an adult. So, at this point we're pushing to try to see more and more of our adult services, uh, having a greater community based orientation so that people don't see it so removed when they are apart of it. Uh, because I don't... I think that's a very good question. Why should I be excited about segregation as an adult when you helped me believe it wasn't a good thing when I was a child?

**QUESTION:**

I want to talk a little... see what your take is on it as in terms that, uh, were around years ago and if there still applicable to the world as we know it today. Umm, and I think first is like the concept of dignity of risk.

**MARK:**

Well... it's interesting when you said; I'm going to go back to some terms. One of the things that I was thinking you were going to ask about is what were some of the... the places that the people of mental retardation were assigned at the state level? Uh, so I hope we get back to that at some point. But this terms... what terms, uh, have helped move our field? You know, uh, one of them is dignity of risk. The current terms that are being talked about include terms like self determination. Uh, but dignity of risk had a...a juxt of position there. It was like, well, how does a successful business person attribute... to what do they attribute to their success? And, they'll give you an answer in two words. Good decisions. And, then you'll ask them, well, how did you get to the place where you could make good decisions? And, they'll give you the answer in two words. Bad decisions. And, so what that says is that everyone whose evolved in their thinking has

done so by having to make decisions and learn from the consequences, natural consequences. Uh, and people with disabilities were withheld from the opportunity to make choices and therefore to have any learning from them. So, if every choice is made in your life how do you make bad decisions to learn from? Now, the dignity of risk concept can get pushed to the place... well, the question is for me now, let's have a dignity of risk\_\_\_\_\_ (INAUDIBLE) here. Should I jump off the bridge or shouldn't I? Well, you don't give people choices over situations that involve life and death. But, umm, which movie would I like to watch. I'm in the theatre here and the all start at the same time and, uh, assuming they're somewhat appropriate... age for their... age and abilities. Umm, why do we pick which movie people are going to pick. And, when they come out, then... then do we learn... did I like that or did I not like it? And, what did they learn from that. So, part of this whole dignity of risk concept was people with mental retardation should have choices. And, choices are the basis upon which people learn. And, choices that are given to people are based on the fact that... and you know it's the way we're referring here... we're talking about people. Uh, and it's people first and people are given choices when we used to think of, uh, people with mental retardation in other terms like retards and other less dignified terms than that. Umm, what we were doing was communicating the lack of respect that we... in... with which we held them. People had never been put in the institutions they were put in. If people had any respect for people with mental retardation as people, uh, so once we started seeing people with mental retardation as more like us than not like us then this dignity of risk concept was there because well, of course, people get choices. So, as we evolved in our respect for people with mental retardation the level with which we were willing to work with them around choices and risks evolved. Because that's the way you treat human beings. So, that was one of the earlier concepts that had us balancing, well, we do everything for people with

mental retardation and we make all the choices, against, yeah, well... and what's so bad about them learning from... from some choices that may not have been the best but isn't that how you learned? So, we went through quite a period there of trying to figure out and are we going to give people the choice to do all things like that or just some things and should health and safety be jeopardized by that? So, I think that was an early stage and a very important one of asking ourselves the question... but, aren't these people first? And, aren't people given choices? And, don't people learn from their decisions more than they learn from ours? You know, watch our kids growing up... we learn more from what they see us doing than from what we tell them ought to be doing. Uh, so that's where the dignity of risk concept came in for me and...

**QUESTION:**

And that was tied in to mainstreaming as well because....

**MARK:**

Well, how this whole dignity of risk concept came into the mainstreaming was families and staff felt like well, gee, wouldn't it be better to be on the top of one pile than to be on the bottom of the other. They were afraid to give people the opportunity to make choices and learn from those choices and to support them in those choices because they were not used to giving people any choices and therefore they assumed that we knew better than they did. And, that we knew how bad things would be because they used to be bad, they would always be bad. And, because people had no information and exposure in the past they would always act as if they had no information and exposure. And, none of that proved to be true. Uh, so people... once the decision... the policy decision was made people's attitudes tended to follow the experience. Umm, in that people were given the opportunity to have some choices. They were given the opportunity to interact in very normal ways with other children. And, what we found was that people with severe

disabilities are perceived pretty readily by other people as significantly different from them. And, while... while they see that they're not prone to be mean or condescending, uh, to those folks as much as they are to want and need information. And, they're willing to interact with them if they know how to be comfortable. And, the way they learn how to be comfortable is from adults. And, if adults aren't comfortable then children aren't going to be comfortable. Uh, so we had to work with the adults to teach them how to be comfortable with people who were different. Uh, and then the adults showing normal interactions and laughing and joking with people who were different gave children permission to be comfortable and just act as they would with anybody else. And, a child will walk right up and say, you know, what's wrong with your eyes? Do your eyes work like mine? And, those questions are perfectly normal and most children with disabilities that can answer them are perfectly comfortable answering them because that's what they live with. 'Why do you have a chair, can't you walk? Umm, answering that question is something we might have been afraid to let a child do before. But, quite frankly it's the most important question they can answer for other people. I'm different and I'm o.k. In fact, I celebrate being different. I'm not... I'm not sitting here pitying myself. I'm not saying that I wish I couldn't walk but I am saying that since I can't, that's who I am. And, you can find me acceptable just the way I am. And, you can be in your space and I can be in mine and we can be together. Uh, we didn't know how far that was going to take us. It's taken us a long way towards people, umm, accepting other people. Uh, one of the reasons that people had such difficulty accepting people with mental retardation living in their neighborhoods as adults was because they didn't interact with them as children. So, all they had was every stereotype they've ever picked up about people with mental illness or mental retardation cause they all got blobbed together and they thought well if he lives in my neighborhood he'll probably pull the bushes up or we'll have your nation on

the streets or we'll have some, you know, they must be contagious because I never see them. Uh, and my children will get whatever they have. And, you know, things... as nonsensical as that but when you have no information you make up information to fill the void. Uh, so this generation of children's growing up knowing Jack and Mark and Mary who are disabled. And, they're the people who are going to be moving next door when they're 35 and they're going to have a different response to that. Uh, they're not going to have a stereotype, they're going to have real names and real experiences to tell their own children about.

**QUESTION:**

Do you think that relationship we're building now with the children is going to be strong enough to keep us from ever going back to the way it was when we told families the only option was an institution?

**MARK:**

We're never going back to the place where we were when all we had was institutions. And, the reason isn't because of all the things it's because of what's in our hearts. We have accepted people with mental retardation as people first and unless we give up on that which I never see us giving up on. And, affirming their humanity before anything else. All the rest of it is a... is a by product of that. S, whether people live in the house that we might want or don't live in the house or have the job in this kind of neighborhood versus this kind of neighborhood aren't functions of whether they're treated because they're people or... or educated or not educated. Umm, we're not going back to the days where people are segregated because children are perceived as children first and people with disabilities second. And, I don't see that changing. Uh, there are economic pressures that everybody faces now to do more with less with government resources. But, I don't see people turning back and saying because we have less funds we're gonna

start seeing children with disabilities as inadament objects again. And, go back to not caring whether they have names and things like that. We're never going back to there. Uh, because people hearts won't sustain it and because the laws of our land have changed to ensure that we never go back there again.

**QUESTION:**

Uh, tell us about self determination.

**MARK:**

Self determination is the current, you know, uh, concept that people are grappling... grappling with in the evolution of how to serve people with mental retardation and how to include them in our society. Umm, it's actually a movement that empowers people by assigning not just choices, uh, about services, uh, to the... and giving them choices about services it assigns money to them. And, they can manage the services because they're managing the money. Uh, and that's a fundamental shift in the entire structure of services for people with mental retardation. Because you become the center of focus when you have the money and the choice. I'm still the center of focus if you have the choices but I have the money. Uh, as we've evolved as a system even though we had segregated services and services for adults what we found was that, we knew what you want maam with your child and it's what we have to offer. Isn't that a coincidence? When even it might not be what you want but since that's what we have to offer, everybody, you know, one size fit all. So, if we have these kinds of programs and everybody went into these kinds of programs when everybody might not need these kinds of programs. So, self determination is... is an opportunity for professionals to step back and say are we over managing, uh, the lives of people with mental retardation, uh, by making choices for them within the resources that are available that we wouldn't need to make. Uh, and what we're finding is that people will be... will accept even less money to have more choice because

it's empowering to have that choice and they get more satisfaction and more results from the choices they make than from the choices we've made for them. It won't change the money we have available. Everybody's limited in the dollars that are available and that won't change. But if people have to be frustrated with what the resources are they're... they're more likely to be satisfied with the limitations when they're directing them. Umm, there's a balance in self determination cause just like anything else, if you're making choices then you have both the opportunity to choose and the responsibility to manage those choices wisely. Uh, there will be choices that people will not be allowed to make with public dollars. Umm, we were talking recently about this thing, uh, would it be a good idea for us to in the self determination to say, you have a 10 thousand dollar, uh, you have access to 10 thousand dollars to purchase services. You can include such things in those purchase... in those purchases as firearms and gambling. Uh, now, most people are never gonna go there and never gonna want to use public money for that, but the public will want to be assured that... there are certain prohibitions on the use of public funds. Uh, and while that's... we'll make those choices to make people, uh, to make clear how public money should be used, but most people aren't asking to make choices with public funds to use those kind of things that people are afraid of. They want the basic things that everybody else does. They want a home where they can be comfortable and safe. They want friends that they can interact with. They want a place to work that is dignified and a place where they can contribute. Uh, and if they're younger they want to be able to be educated in their community not apart from it. These are not unreasonable things. Uh, so when people get to be able to direct money through self determination and have limitations they want to do the things that everybody else does anybody... anyway. Uh, my experience is that people are limited not by their disabilities but... but by the fact that they're poor before they're disabled. And, people who are poor have fewer choices

in what they can do with their resources than people who have lots of funds. So, before somebody is in a wheelchair, they're poor and in a wheelchair. And, not that... not that everybody is but if... if all you have is, umm, your disability and you're limited in what you can make because of it, uh, the fact that you're poor limits you by far more than the fact that you, uh, have a disability. So, self determination I think isn't just a, umm, an idea or a new program, well... well, we'll shrink this program and we'll make this program a little bigger to make room for self determination. Self determination is a way of seeing consumers and their families and empowering them at a greater level than the more condescending and, uh, limiting perspectives that we've been offering them in the past.

**QUESTION:**

Where is that concept coming from? Is it being directed by legislation? By... at the state level... at professional level? Where... where is that coming from?

**MARK:**

Well, the motivation for, uh, self determination is coming in the same place that the motivation for children being educated with other children came from, people with disabilities themselves. They're saying, you know, one size doesn't fit all and I don't need this, in fact, this is more expensive than what I need. I need this and what I want and what I need can sometimes be the same. Uh, most people with disabilities are not asking for wants that aren't needs. Uh, you know, I might want to have a child that goes to Harvard but I can only afford Kent State, uh, and people understand the difference between wants and needs. Uh, so people with mental retardation and their families are very reasonable and very responsible about how they want to use resources. The motivation for self determination is their frustration that they have so little opportunity to direct the services that affect them so much. We have families, umm, that are in their 80's we have over 15 families in Montgomery County who are in their 80's with children

in their 60's living with them. Now, you would think that they could tell us something about how the supports they would benefit most from would, you know, how those supports should be structured to mean something to them. But, even now we have structures that say this is how this support is and this is how this support is. So, we're moving to blend more with the needs of consumers and the wants of consumers where those wants are reasonable. And, they're usually very reasonable. The motivation then for self determination comes from people knowing that they can do a better job than we can and helping us to learn that, you know, we can step out of the way a little bit.

**QUESTION:**

Well, what do we need to do in communities though to make sure that this is what families and this is what people with disabilities are telling us but what... what's the message we have to do in the communities now to make sure that the resources are going to be there and the support is there because these things do take financial support. So, what's the... what's our work in the community to make self determination possible for people?

**MARK:**

Well, one thing that's very necessary for self determination to be a possibility or for any services for people with disabilities is to continue to promote the dignity of people with disabilities. Everyone in our society... we're very driven by productivity in a particular line of thinking. Umm, let me tell a story to demonstrate that. Umm, when I was managing the Stillwater Center, which is a large intermediate care facility for people with mental retardation in this community. One of the individuals, uh, died and I was talking to the mother about the arrangements for the funeral and she said, well not many people knew my son so I don't think we'll have wake, we'll just have a funeral and the burial. And, I said, I think you're missing something here. You're assumption is that not many people

will know of his life and therefore would not know or be touched by his passing. I said, I think you're really missing something here. Over the years, many people have cared for him. Many people and your son has touched many lives in ways that are irrevocable... can't be taken back. And, their hearts are forever changed because of the interaction. I'm getting in touch with the, uh, nature of what those... those, uh, communications were about. And, what those relationships mean to people. Umm, so we... we had a wake and we had to double the space because of all the people. Because of all the people that came. And, it was because of this person's humanity, uh, not because of what he made or how many stocks he had. I mean, think of the richest people you know. Think of the most business, uh, the most... the stock wealthiest and the most property wealthy people when they die people don't stand up and read off their portfolio. People don't stand up and say, umm, he had 400 thousand shares of this and he sold at the right time and I'm so proud of him. You know, I mean, that isn't the way it works. People talk about whose hearts you've touched and whose hearts you haven't. And... and, what a legacy you've left in the hearts of people. Uh, they don't say, and now can we finish the funeral so we can get to the will? And, even though some people might feel that, that is not what productivity is about. Uh, so our world is tied up in a conception of productivity that is based on income and income taxes and what you buy before Christmas. But, the world of hearts does not revolve around that. Uh, the world of hearts is where we live and, uh, what make Thanksgiving and Christmas worth going through. Uh, and that's where people with mental retardation are the most productive. They help people be genuine. Uh, where they might not have permission to be genuine elsewhere. They help people get in touch with their own sense of humor and their own sense of simple things can be fun. Simple things can... can be the whole thing, can be it. Everything doesn't have to be complicated and expensive to be, uh, enjoyed, uh simple enjoyments, uh, smiles are

enough. Uh, so one of the things that we're going back to is what is productivity and who's productive? Uh, so part of what I'm, I guess trying to say in this is that the whole process of trying to figure out where respect comes from for people with mental retardation. Is how we value them and if we can value them as human beings first and say, well what is the purpose of being human? Without religious connotation but ask it in your heart for whatever... whatever answer you come up with. Umm, people with mental retardation can be some of the most productive people you know because they open more hearts. They help people be genuine. They... they're not manipulative. They're... they are genuine. Umm, and what you see is what you get and if they could say that about me on my death bed I'm, you know, I'm... I'd be there.

**QUESTION:**

You talked, uh, when we started talking about some of the normalization and the dignity of risk and all you said, you thought maybe we were going to talk about some terms and concepts. Maybe the times of institutions and all. Talk about what you were thinking there.

**MARK:**

Well, you know, one of the things if you track, uh, the field of mental retardation, you know, uh, I would say that the field of mental retardation has made more progress, you know, in seeing people with mental retardation as people in the last 35 years than any other civil rights movement of any kind. And, I see the field of mental of retardation as a civil rights movement more than I see it as anything else. Because, these people were discriminated against for who they were by definition. And, they were marginalized by stereotypes that, umm, were based on mis-information and fear. And, that is what the... the definition of discrimination is. Uh, and in the past 35 years we've gone from hell holes which you very well documented in this whole process, uh, places where I interviewed in

one day after getting my Masters Degree in this field in 5 different components of one major institution and where... this wasn't one where I had done any consulting work but I knew of it. And, umm, I got to pick whichever job I wanted when it was all done. And, I turned them all down saying that I didn't think this is they way people with mental retardation ought to be living. Uh, and I wanted to pursue... bring about change from the outside. (COUGH) But, I lost my train

## **RESTART**

So, people with mental retardation then were only placed in these places because we had limited perceptions of what they were capable of and when you call a person an idiot and... and you have washed over them all that, that emotionally means to you, umm, you can put them anywhere. So, we've gotten to a place where we have more respect and when you have more respect you don't act like that anymore. Uh, the other thing is, if you follow the names of the departments, just in the state departments that... that had the responsibility... you're following the degree of respect of the people themselves that we hold them. Guess what the first department was? You might know the answer to this. O.k. The first department that had a responsibility for people with mental retardation in the State of Ohio was the Department of Corrections. So, we were so afraid of people with mental retardation that we decided that places where we would put them would be comparable to jails. And, they lived up to that expectation I assure you. I've been there, I was there. Those places were prisons and worse because we had more respect for prisoners than we had for people with mental retardation. They were given names. They didn't have shoes poured on the floor and fight for them. They didn't have some of the things that we have for... for the abuses and people with mental retardation. Then it went to Mental Health because you had to be crazy if you were mentally... if you had mental retardation. So, we had this hodge podge of mental health and the dilemmas and

limitations that people perceive people with mental retardation with and quite frankly, the stereotypes that were mis-informed about people with mental illness. Again, people with mental illness. Umm, then it was Mental Health and Mental Retardation cause we figured out, maybe there is a difference here we ought to do something to treat them a little differently. Mental Health and Hygiene was in there. They were somewhere in there before Mental Health and Mental Retardation. Then it was Mental Retardation. Then it was Mental Retardation and Developmental Disabilities. And, that's where we stand today. But, it's... it's a progression of lack of respect to respect. And, it all comes from perception of people's basic humanity and affording them the same rights that other people have. Uh, and checking your stereotypes before you act, before you watch what comes out of your mouth, see what... she what's driving that thought. Uh....

**QUESTION:**

One of the things we've seen is... especially with the families and doing this in Akron and everywhere else we've been, umm, and most of those families since we had a lot of focus on the institutions initially, uh, are older families. And, even today with Julia and John who made the decision to keep their... their sons and daughters at home with them. Umm, they're... you talk about.. you mentioned, you know, there's no way because of who we've changed as... as a society and who we are as people that we would ever go back. What can we through this project or through anything else do to take away the fear that is still in the hearts of families that have been through that. Is there ever a way that that fear is ever going to leave them?

**MARK:**

So, is there ever a way that the fear of having gone through (AUDIO OVERLAP) that it would go back.

**RESTART**

That's like asking the people who have gone through the concentration camps what can I do to take away that memory and that pain. And, it can't be done. Uh, I think what you can do is give them confidence that there's no reason to believe it will happen again and accept the fact that that's part of their perspective and part of their experience. As professionals there's nothing I can do, absolutely nothing cause I've tried to tell a parent who's afraid to take the risk to let a very competent son work in the community, who's afraid because of discrimination that's taken place in the past. But, there is somebody who can tell them that it is o.k. to take that risk. And, that someone is other parents who've taken the risk and other consumers who've taken the risk can talk to their sons and say, you know, I was afraid to go work at Arby's and I was afraid that I wouldn't be able to make the bus or do this or to do that. But, I worked through those problems and they were as solvable as the problems in the workshop (LOUD BACKGROUND NOISE/VOICE) were and you know what I make a heck of a lot more money doing that. Now, I could never (LOUD BACKGROUND NOISE) tell them that cause I'm the institution but other parents can tell them that and (LOUD BACKGROUND NOISE)..

**END OF TAPE**