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ORAL HISTORY INTERVIEW WITH PETER BISBECOS DECEMBER 4, 2012 INTERVIEWER: PHILIP STAFFORD VIDEOGRAPER: PEGGY HOLTZ

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**PB:** PHILIP STAFFORD **PB:** PETER BISBECOS **PH:** PEGGY HOLTZ

## [00:00:10]

**PS:** And sound is okay. I'll let you identify yourself and get going?

PH: And look at --

**PS:** Yeah -- And look at me rather than the camera.

PB: Oh. You want me to look -- Okay. I was -- Okay. All right. Well, Hi. I'm Peter Bisbecos. I live in the Indianapolis area. Legally blind from birth, if you want to take the IRS definition of blindness seriously. I tend not to. And I have been involved in the disability arena on and off for the last 20 years.

**PS:** Good. So can you go back to the beginning 20 years ago and talk a little bit about what you were doing and what drove you to get into the work that you have done.

#### [00:01:01]

PB: Actually, the answer to that begins a lot earlier. I entered first grade in 1967 prior to the Rehabilitation Act so there was no right for me to go to a public school. And the principal of my grade school in Missouri in Saint Louis where I lived at the time wanted to send me to a Missouri School for the Blind. My parents didn't want that. I inherited my vision from my mother and she knew what I was and wasn't capable of doing. And so no offense to the schools for the blind, but she knew I didn't need that. And I had a first grade teacher who understood disabilities because she had a grandson who had what we would today call an intellectual disability. Back then, talking about historical perspectives, it was severe mental retardation. But she understood and stepped up and helped us or it might have been a real

# **Indiana Disability History Project**

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fight. But what I learned is that I had to prove myself constantly, that people with very good intentions just didn't think I was capable of doing things because of my vision. They wanted to protect me.

## [00:02:02]

They wanted to keep me from having hurt feelings. All the things that keep people with disabilities back. And I just knew from home that never would have been tolerated. So I wanted -- always wanted to be a lawyer. And I became a Marion County deputy prosecutor. And those who don't know Marion County and Indianapolis, Indiana are the same thing. It's an incorporated city county situation. And what got me in to the disability arena actually wasn't initially intentional. Because I was so accustomed from grade school and beyond to learning to have to stand on my own that I didn't want to be associated with disability issues because when people learned I had a visual disability, even if they'd seen me function and had no idea, they started treating me differently. But the Marion County prosecutor was elected mayor and I had the opportunity to go to the mayor's office and he asked me to work on the bus system. At the time I couldn't drive, and I can now, but at the time I couldn't. And he wanted me to work on bus issues.

#### [00:03:03]

For those of you who know the Indianapolis area, we have a bus system that needs a lot of work and we did then as well. The Americans with Disabilities Act had just become effective less than two weeks before I joined the administration. And we were out of compliance so my first job was to get the bus company into compliance with the Americans with Disabilities Act, which we succeeded in doing without litigation, something I'm pretty proud of. And then from that point the ADA compliance for the city, not the human resources side, but the physical compliance, all the infrastructure and programs, the city buildings and so on, needed a lot of help. I had been putting out fire after fire while I was working on the bus company. So when we got that in shape they asked me to take over the whole compliance responsibility. And that's how I got in to it. It was not an intentional. Not only was it not intentional, but I had intentionally stayed away from disability issues until that time. But what that taught me, what I learned, was that I think people with disabilities have unique leadership opportunities.

And my leadership in the community has been to help people realize that and try to bring that out.

**PS:** And from the prosecutors office you went in to state government.

**PB:** No. Not quite.

**PS:** Was there an lapse there?

[00:04:26]

PB: Yeah. Let's see. The prosecutor's office to city government and then there was an administration change and I had a vacation from government for about four years. And when Governor Daniels was elected in 2005 I rejoined government going in to his administration to run the Family and Social Services Administration's Division of Disability and Rehabilitative Services, which is probably the single largest disability services delivery agency in the state. We served over 40,000 Hoosiers a year with

disabilities, about a 1.2 billion dollar budget, seven divisions. I closed the last institution that we had during my tenure and we did some other things that were first in the nation services like the statewide crisis management system. All with the intention of building a system that helped focus on outcomes and helping people maximize their independence.

[00:05:24]

**PS:** Going back to the kindergarten, I guess, you were talking about the prospect of being directed toward the blind school as opposed to the public school system. So you did go in to public schools or --

**PB:** Right. I was in the public school in kindergarten, but when I hit first grade for some reason the principal thought that I should be in the school for the blind.

**PS:** But you avoided that?

**PB:** Yes. Completely.

**PS:** How did that -- Did that require litigation?

PB: No.

[00:05:54]

**PS:** You didn't have to go to court or --

PB: No. My folks didn't have to sue anybody. There wouldn't have been a cause of action in 1967. There was no civil rights law that said I had a right to a public education in a public school. What happened was my first grade teacher, as I said, had a grandson with what we then called profound mental retardation. And she was from an influential family and had a lot of political savvy. And she took the principal or would have been a much bigger fight than it was. I do have to say, in his defense, that was not done in 1967. We moved here to Indianapolis in '72 and he called the principal at my grade school here in Indianapolis and said, "Don't worry about it. It's fine." So in the process he learned that it was okay. It just took -- It took five years.

**PS:** Yes. [Inaudible] in the end --

**PB:** Yeah.

**PS:** That's neat. Yeah. Have you ever thought about how your life would have been different had you gone to the blind school?

[00:07:00]

**PB:** My parents would have found a way to put me in private school. They were -- again, my mother has the same visual disability that I do. And she didn't go to -- she had to go to a special program when she was in high school because there was nothing -- she couldn't read the print in the regular schools. And at that time optics were just not sufficient to help. So she had to do that and she didn't want that

experience for me. And frankly it just wasn't necessary. Those schools help a lot of people, but I wasn't one who needed their services.

[00:07:35]

**PS:** So when did the law change?

**PB:** Well, the Rehabilitation Act of '73. I think it's '73. I'm terrible with math. It's either '72 or '73.

**PS:** These are federal --

PB: Right. It really reflects the beginning of the change. That law didn't have a lot of teeth. And the Americans with Disabilities Act which passed in 1990 became -- largely became effective in 1992 -- was the real stepping off point for putting teeth to the law and changing things. But what I would suggest to you is that what really made the difference, in my opinion, is physical access. As we've built buildings -- we've got in to this very heavily in the 1990s. Just down the street from us is a Conseco Fieldhouse. It was the first major sports facility built post ADA that didn't experience litigation because we learned from the experiences of other cities and we heavily involved the disability community in planning what we did. It's a tremendously accessible facility. When you see that, when you see curb ramps and accessible buildings, and then people now see folks in wheelchairs and don't think much of it, 20 years ago that was a big deal.

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And as you see more public -- I wouldn't say acceptance. Assimilation because people can get where they want to go now, people who are mobility impaired. I just think it makes a huge difference. Once people become a part of society then there's a higher level of consciousness and we just don't have the challenges, I don't think, that we had then. There are different challenges, but I think we've moved nicely along the path towards inclusion.

[ Background Discussion ]

PS: Some people would argue that the ADA, as effective as it has been, sets floor rather than a ceiling and that progress has been incremental mostly through litigation and individual advocacy and group advocacy as well, as opposed to an approach that would have identified the ceiling and pulled together the various groups in the community who could actually benefit from these changes, not just people with disabilities. So there's some discussion about that. Do you have some thoughts about whether the ADA was the way to go in terms of fostering change in society?

[00:10:41]

PB: Well, I think that when you start -- And I'm not sure what people say when they say that the ADA should have been the ceiling rather than the floor. When you begin to identify specific groups and to say, "This group needs to be treated this way," And I don't know, again, what the ceiling is. But let's just, for purposes of argument, suggest that maybe it's you need to have [inaudible] or something of that nature. If I'm being unfair to those folks, mischaracterizing, I don't mean to do that. I think what you do is you

set people apart. And I don't view -- I don't have the most popular or the most common view of disability issues. But I think that comes from my perspective which is the advantage of not necessarily being recognized as having a disability unless I tell some people. And I think that having a disability gives people a leadership opportunity that other minority groups don't have. I mean if you think about the difference in gender or race what you say is, "You're this.

## [00:11:43]

I'm that." And then that sets up some sequential thinking about how we're different and we will be forever. I think with disabilities what happens -- And, again, friends have talked to me openly about -- frankly about their feelings because they don't think of me as having a disability. It's, "You're this. I'm that. And in the blink of an eye I could be like you." And that scares people, initially. So you have this same kind of fear factor that you have with, let's say, race or gender differences, but the distinction is as people see you, somebody with a disability succeeding, and then they say, "Well, if that ever happens to me, I now know that my life isn't over." And that's a very powerful thing. And that's when I say people with disabilities have a leadership opportunity. That's what I'm talking about. And what I like about the ADA and the way it's gone is it has literally erased physical barriers which were a huge problem and it's allowed people with disabilities to exercise that leadership.

#### [00:12:43]

And meld themselves more naturally, I think, into a community. I think it takes longer, in one respect, but I think it's much -- The roots are deeper and it's a much more permanent change in the long haul. So I believe that's what happened is a very healthy way of changing society.

- **PS:** Are there changes that need to happen with ADA or you know broadly with other kinds of social policies that [inaudible]?
- PB: Well, I think that, again, I'm kind of a pragmatist when it comes to this. I don't have an ideological viewpoint on it. I've always been troubled by Title I, which is the employment section because I don't think it addresses the problem that leads to the high unemployment amongst people with disabilities. Yeah, there is some prejudice and there is fear and people don't get hired sometimes because an employer doesn't want to dig in or take the risk that maybe this person can't do the job. But President George W. Bush used a phrase that I've always liked and it's something the disability community has suffered from and I use the words "suffered from" intentionally when I say that, and it's the soft bigotry of low expectations. So what happened -- and people tried to do this to me. I just know that my parents wouldn't have tolerated it if I'd accepted it -- is to give you a lower standard. To say, "Well, he's going to have such a rough life let's just cut him a break.

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Let's not hold him to the same standard as everybody else." And let's make his childhood easy because it will be the last happy time in his life. I mean I've actually heard people say that. Well, what you do if you don't have the opportunity to experience failure in one form or another and learning to pick yourself up and move on is that you're not ready to work. So who -- as an employer who would you

want to hire, somebody who knows how to bounce back, figuratively speaking, or someone who says, "Oh, well it's the end" because something went wrong? And I think a lot of people with disabilities are ill equipped to work because they've never had that experience. What I always think of is the early '70s -- I think it was the early '70s. There was this wonderful commercial for Life Savers. It's usually a son and his father are walking away from the camera and he's -- the one I remember he's in a baseball uniform. And his head's kind of down. He's -- it's clear that they've just lost the game. And dad gives him a roll of Life Savers.

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And anybody who's been in that experience, and I've been the last kid to strike out, and with my eyes that's not surprising, but that's a different story for a different time. You learn that you feel horrible but the next day you show up and your friends are still your friends. Well, if you don't have that experience it makes you much less employable. So I think we have to take a deeper look at the root cause of unemployment because I think a traditional civil rights approach by itself is actually -- and this is definitely not a popular viewpoint -- I think it's hampering employment for people with disabilities. Beyond that I like -- again, I like the way that things have developed. And they haven't gone far enough yet, but when you get to know somebody one on one it's a much more powerful thing than saying, "Oh, that's your civil right" because then you want to make it work. But I think we also have to look at the trends in our country because what's happened at this point is accessible design will become increasingly relevant in the next 10 to 15 years if we have baby boomers retiring at what?

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10,000 a day? The fastest growing group of senior citizens is over 85, which means people who have more intense physical needs are living much longer. And if you think about just the growth and demand and the growth of that population, we're going to experience that until at least 2055 when the youngest baby boomers exceed 85, if I've done my math correctly, which wasn't one of my strong points in school. You have kids with autism today. I mean in 2007 look at the CDC's estimates that kids eight years and younger. The incidents were 1 in 150 and today in 2012 that has gone to 1 in 88. So it's almost doubled in five years. So we're going to see a much greater growth in the autism spectrum and we have people with disabilities living normal life spans. Having been responsible for delivering those services, you look at the age curve and at one point in time you say, "Well, okay, we can keep things going because we have people who will die off in their twenties."

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Well, thankfully that's not happening anymore. But the reason I go in to this is a population between seniors and just people with disabilities is growing at such dramatic rates that inclusion will become a much more common thing than it ever has been. And you don't want to -- I don't think we want to do something that would close that off. And I'm afraid that getting too aggressive about demanding certain specific things might actually close off what I think is the beginning of a more natural inclusion. And, again, I'm not a subscriber to the normal civil rights thought process that applies to other areas because I think disability is very different and I think that the civil rights approach to disability needs to be

tailored to that. And so I think we have to experiment with that and try to figure out what the best approach is going forward to ensure that the roots that are now taking hold aren't pulled up.

[00:18:33]

- PS: So are you implying that in some sense if not disability then at least some limitation the individual might have is going to be the norm? And that you're really talking about cultural change, a real shift in the way we think about humanity and what's normal and what's natural?
- PB: Yes. I believe that as aging and disability life spans continue to grow at increasing numbers in our society that more and more of us are going to have disabilities. And what happens is frequently it's personal. You don't know -- you don't really understand senior citizens' issues until you have a parent who's going through it. You don't understand disability issues until you have a friend or a family member who's going through it. But once you do it gives you a different perspective. So if you just look at the sheer numbers things are going to change on a personal level. And let's do things that can grow those changes as opposed to putting them in to a legal framework that makes people freeze up and say, "Gee, if I say the wrong thing I'm going to get sued."
- **PS:** So how is our country going to look? How's it going to look in 2035 and how will it be different?

[00:19:54]

PB: Well, this is going to be on YouTube, theoretically, and it could be there forever, so going back to my law school training I'll issue a disclaimer that I could very well be wrong. But you know what scares me, first of all, is that at the same time we have this explosion and growth in the aging and the disability world we have a workforce, the traditional way of delivering disability services, which is also aging. If you look at the workforce as a whole in 2010 it was just a little over 19 percent that were over 55. By 2020 that's going to be 25 percent and you can just take it out over the next -- I think that right now the tail on this demand growth will occur in 2085. And that's if -- That's when an eight-year-old with autism today would be expected to pass away. And that would -- so it goes up to 2085 if autism diagnoses drop dramatically today.

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I think it will be longer than that. So we have shrinking staff in traditional service delivery systems at the same time that we have radically growing demand. So how does society look different? Well, what's happening around the country and happening in Indiana, and if it's done properly I think it's a very positive thing, is the family is becoming more heavily involved in services than it was in the past. The family is the natural place for a child. If you're saying, "What's the least restrictive environment for an individual, the most integrated setting?" Well the average 17 year old lives with mom and dad, hopefully, or lives with a parent hopefully, and maybe siblings. Well, that's -- and those family structures meet that individual's needs. Well, that's what's going to have to happen on a more regular basis with people with disabilities. Maybe much later in to their lives. Just because there won't be enough other human hands to serve them. That's what's going to happen with senior citizens. Families

will become increasingly involved with their elderly parents or elderly relatives or maybe even friends and neighbors.

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And so the family becomes more involved. And I think just by extension the community becomes more involved. And so people who had been segregated will of necessity become more integrated if we do it properly. I think it's a very positive thing.

**PS:** Does this require some redefinition of what we mean by family? And will changes in housing follow that?

PB: Well, I think we have to reexamine everything we're doing. Certainly what you call family will change because it has to. You know, you go back 100 years and you had grandparents, parents, children, and grandchildren living under the same roof or in very close proximity to one another. And they became more mobile and the family kind of splintered. Well, I think just again we don't have the resources to continue to sustain that lifestyle. So it could draw people back in. I think that's the most reasonably foreseeable thing. Certainly there will be other things. I mean you see homes -- Illinois has a particularly successful program. It's kind of like a foster home program where people -- they're paid by the state, but they bring someone with a serious disability in to their home. Well, there's a point at which -- it fits particularly if they get along -- I think family just got redefined. Because they become effectively members of the family.

#### [00:23:25]

So I think we'll see a lot more of that, and certainly I think the answer is, yes, we will see changes in the way we view family. But beyond that I wouldn't hazard to guess because, as I said, once it's on YouTube it never goes away. And I don't want to be totally wrong.

PS: You know much of our housing, our suburban housing in particular, is designed for, you know, two parents and one and a half children. And I think we need to expand their [inaudible] because the zoning doesn't allow, you know, the larger families or unrelated people living together or -- So do you envision new patterns of living in communities?

#### [00:24:12]

PB: Well, I'll give you an example where that's -- I think that's happening. It's called The Village of WestClay. It's in Carmel, Indiana. And if you go up there it's a really intriguing mix of housing. Now it's very high end housing, but you have kind of the close in village which is -- the houses are made to look like they were built in the 1800s to really 1900s. The houses are closer together. It's that more Norman Rockwell quaint type thing. You go a little bit out and you have the bigger more traditional suburban homes. But right across the street with connecting bike paths and everything else that you would expect to keep them connected is a senior residential community. Now, it's not a nursing home. They've got independent living homes which are freestanding. They all look alike, but they're very attractive. And then you've got progressive levels of care. And the way they were billing this when they built it is, you know, you can live here and mom or dad or maybe both could live there and the kids can go see them.

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And it's all one big community. And, you know, frequently when you start off with something like that you've got to start off -- Frequently you start it off with people who have needs and then the concept gets developed and it becomes -- You know, money is always the issue here. I mean that's the bottom line on so many of these things. As you figure out how to make something like that work then it can be replicated elsewhere, but you have a lot of freestanding houses today. I mean hundreds of millions of dollars in development and there are good things and bad things about that. In neighborhoods built in the last 20 years you go down the street and they're very uniform, but the nice thing about them, having had a 100 year old house and now having a 15 year old house, is that 15 year old house sits up on a hill so when it rains the water drains away from it. And you have a better, I think -- better amenities, in some respects. But also you have to get in the car to go every place, including I have to go in the car to go see my mother. It would be much nicer if I could just walk around the corner and do that.

So there are challenges, but that infrastructure's already in place. And I can't see us ripping it up. So we'll have to get creative about how we do those things. And, again, use of technology is one way. But nothing beats the in person contact. I can't envision how that's going to change, but it has to.

[00:26:38]

**PS:** Let me just end up by asking what you're doing these days.

PB: Well, when I was at FSSA, the Family and Social Services Administration, I had the opportunity to do some really creative things. Because we had a -- believe it or not, we had a consent decree with the Department of Justice and we closed our last institution for people with developmental disabilities and used the savings from that and some other things to grow the system by a third and create several first in the nation services. Including a statewide crisis management system. We did some recent changes to case management. We started to build a way in which we changed assessing people so that there's more of a personal outcome based system rather than the traditional institutional input based system. And now the Department of Justice in 2009, late 2009, launched a campaign to enforce a 1999 U.S. Supreme Court decision called Olmstead vs L.C. where they take people out of institutions and they expect states to build more robust communities. Well, many of the things that we did here in Indiana they're now requiring other states to do.

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They've brought -- I think they've announced five consent decrees since 2009, for instance, and all of them require a statewide crisis management system, something that hadn't been done before we did it. So I'm working my way in to that mix, hoping that the experience and some of the mistakes that we made might benefit others.

## [00:28:09]

**PS:** Yeah. Cool. That's wonderful. That's great. So you're doing more traveling. Well, thank you very much.

**PB:** My pleasure.

**PS:** Unless there was something else specifically that --

PB: No.

[END OF INTERVIEW]