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**ORAL HISTORY VIDEO INTERVIEW WITH
DAVID NELSON
DECEMBER 3, 2013
INTERVIEWER: JANE HARLAN-SIMMONS
VIDEOGRAPHER: PEGGY HOLTZ
RECORD ID: 099-DO**

DN: DAVID NELSON

JHS: JANE HARLAN-SIMMONS

PH: PEGGY HOLTZ

[00:00:10]

DN: -- first Center for Independent Living in Indiana.

JHS: OK. Well, we haven't started yet.

DN: But just so you know. So-- And I've been there for 23 years. Before that, I was with Vocational Rehabilitation going back to '76.

JHS: OK.

DN: And was a supervisor. And today in school, a certified rehab counselor.

JHS: So maybe you'd like to also talk about what things were like with voc rehab in that era.

DN: Yeah. And that would be pretty positive discussions, especially compared to now, and I'm not sure. I mean, it's changed probably for the worst.

JHS: That's kind of what we're looking for is that sort of, you know--

DN: Yeah.

[00:00:46]

JHS: -- how things have progressed or in some cases not progressed--

Indiana Disability History Project

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

[00:00:49]

DN: Yeah.

JHS: -- over the years as it relates to the state of Indiana, so.

DN: Well, that would be, you know, I do have that background in working with rehab facilities and--

JHS: OK.

DN: -- and the employment part of it, and worked also for the passage of the ADA in the late '80s, I was part of--

JHS: Great. Well, you're obviously something, there's a lot to tell us. So, what we do is when Peg edits the video, the questions, my voice will not be heard. So if you can put your-- in your answer basically put my question as a statement, that will really--

DN: OK.

[00:01:25]

JHS: -- help.

DN: OK.

JHS: Does that make sense?

DN: Yup, sure does.

JHS: Great. And then, you can look at me rather than the camera.

DN: OK.

JHS: And it's very informal. So, if there's something that we don't ask you, if you want to say, just go--

DN: OK. That sounds like a winner. All right.

JHS: So, we'll start by asking can you tell us your name, where you live, and where you were employed.

DN: I'm David Nelson, live in Fort Wayne, Indiana now, employed by League for the Blind and Disabled in Fort Wayne. It's a Center for Independent Living that is serving 11 northeast counties of the state.

[00:02:02]

JHS: And tell us about how you got involved with the League for the Blind and Disabled.

[00:02:08]

DN: I got involved with the League back in 1990. I was working for the state of Indiana for Vocational Rehabilitation. I'm supervising Vocational Rehabilitation counselors in four counties. And I had a staff member, a counselor tell me that I didn't belong there anymore and that I should be looking for something else. And she, I think, was concerned about some of the limits that you have when you work for state government. But the League was a Center for Independent Living. It was in trouble at the time. It served only people who were blind. It was then called the Allen County League for the Blind. And it had become a country club board and kind of an organization that lost touch with the people it served. It was a Center for Independent Living. But back then, the regulations were such that you could technically serve one population. The law back at that time said that you had to serve people with a variety of disabilities.

And the argument was, well, 75% of people who are blind have other disabilities. Therefore, we served people with a variety of disabilities. It was a loophole, did a lot of Centers, single disability Centers used back in the '80s, but--

JHS: What was that law that you're referring to?

[00:03:30]

DN: I'm referring to Title VII, the Rehabilitation Act of 1973 as amended throughout the years. Title VII established Centers for Independent Living, piloted five Centers to help develop the model that the feds wanted to go with initially in the '70s. They piloted five Centers, groups like Paraquad in St. Louis, the Center for Independent Living in Berkeley, California, and three others that I forget. But in the late '70s and early '80s, they started rolling out the funding for Centers for Independent Living. And our executive director at the time, Frances Shine went after the funds. The law at the time said that you had to serve people with a variety of conditions. That meant a single disability group could go after it. And the law also gave the first right of refusal to state government. So if the state government said, we want that money from the feds and we will administer it, the state's got it.

Indiana opted not to take that money. And the law was written-- the regulations were written to say, if the State opts out, then the feds will contract directly with the nonprofit organizations. So, that's the way the law was back then. And the League-- after the state opted out, the League went after that money and got it. Now it was a single disability organization, not what we consider Centers today. And the League was one of many organizations in the country. They did that. Today, they could not do that. The law and the regulations are tight enough that you can't exclude people from your services based on the presence or the absence of a disability. So it's much cleaner today.

[00:05:23]

JHS: Were there other states then that opted out like Indiana did?

[00:05:27]

DN: Yes, the majority of states in the country opted out. The law also said that if the state government put in more Centers for Independent Living money than the feds did that they could administer the federal money if they chose to. So there were some states that did put in more money but they still chose not to, over time, administer the federal money. So I believe at this point, there's only-- there are only two states in the country last I knew that managed that Centers for Independent Living money that that money came through state government to go out to Centers. I think only two states in the country now are setup that way. So Indiana wasn't unusual in opting out. But it created enough-- an environment that a nonprofit could go directly at federal government and go after those funds. A lot of times, that money comes through states or counties or other sources. Most Centers for Independent Living money from the feds, Title VII money, Part C that amount set for Centers goes directly to Centers for Independent Living from Department of Education.

JHS: And is that the same today as it was back then. Has that remained the same?

[00:06:41]

DN: Yes, most and there's a couple pots and money that states use-- several pots of money that states use. Title VII has a section of the Rehab Act has a Part C section that I-- that is the enabling legislation for Centers for Independent Living dollars, federal dollars. Most of that goes directly to Centers. Title VII also has another part, Part B dollars that can be used for a variety of sources including the support of Centers for Independent Living. Now those Part B dollars do go to the state but then the state can put them out for a number of things, surveying, needs stuff, just a variety of things that they can do. They can support state Councils for Independent Living with it. And they can fund Centers for Independent Living. So, those Part B dollars continue to go through the state as they always have under a different title at the time, you know, those title headings have changed with reauthorizations.

But those now Part B dollars have always gone through the state and they continue to. And a chunk of those dollars today in Indiana do come from the state too to Centers. But the Part C, that federal enabling stuff for Centers, funding for Centers for Independent Living, that goes directly to Centers in most states without going through the state.

JHS: So, it sounds like the funding hasn't changed too much. Are there things that have changed in the Independent Living Centers in--

[00:08:15]

DN: Well, the feds eventually tightened up the requirement on cross disability in other words serving people from all groups of people with severe disabilities. They have tightened up that language, we knew that was coming. The feds over the time from the late '70s to today set up-- they always had a set of standards and assurances in the regulations but they set up a set of-- they defined what those standards were. They-- over time, the regulations have grown to be very specific on when it says the standard is across disability, what does that mean, what Centers have to comply with. So, that's evolved. That's-- Yeah.

[00:09:13]

So, the standards we now have what they call indicators for those standards so that we know if you meet these indicators, you're in line with this particular standard. So, that's grown over time. There has been a growth in federal Part C dollars over time. Now, it's been stagnant for many years now. But there was a time when we had an influx of Part C money, federal Part C money coming in to Indiana that we used to start a number of Centers at that time. So, there had been some pretty significant changes. And now we're looking at another potentially significant change in the Rehabilitation Act and in Title VII, Independent Living title with the new reauthorization that we're trying to get through. Independent Living at the federal level is under Rehabilitation Services Administration in the federal Department of Education.

And we're trying to get it out of the Department of Education. We are not that. We are human service. And that's where we belong. And we're also trying to get Independent Living set up as its own federal administration. Because right now, Independent Living is buried so deep in the federal bureaucracy that it's hard to have a voice at high levels of federal government because we're buried so deep. That needs to change. People with disabilities' voice should not be muffled under three or four layers of other interest groups. So, that has changed and we're hoping to see another major change with the reauthorization if we can ever get that through Congress. I mean, we have a bipartisan bill in the Senate right now that was crafted by both Republicans and Democratic leaders. It's there right now. Whether the Senate, whether the House will let it get through, we have no idea, so.

[00:11:16]

JHS: What about changes at the state level, is there any legislation pending or anything that's been proposed that relates to Independent Living Centers?

DN: Well, that's a great question. Years ago, the-- we'll go back to the federal law, the federal law gives us what the definition of Centers is. And if you are a residential service provider, you're not in line with the definition. So, the definition is the basics. Then it gives us standards and assurances and the indicators for the standards. So back in the '90s, we worked with-- in the General Assembly, we worked with Senator John Sinks I think it was and a House member too and I can't remember his name. We wanted to include the federal requirements in state statute. The idea was that if state money becomes available for Centers for Independent Living, we want to be sure that that state money goes to organizations that meet the criteria for Centers. We didn't want a nursing home saying, we are a Center for Independent Living, we're eligible for that money, that state money because it's not federal note we're talking about.

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So, there was a definitions bill I believe for autism on the table that John Sinks and a House member, both General Assembly-- Republicans and the General Assembly. But they allowed us to tack on amendment to that definitions bill. And in that amendment in state statute, we defined what Centers were and we mirrored the federal regulation in state statute with the idea that we want to protect those state dollars to make sure they're going to what they were intended to do. We didn't want the politics of the special interest groups convert those dollars. So in Indiana, in the-- I'm guessing it was

maybe mid-'90s, maybe a little earlier than that, we got a state statute that took care of that problem. That was a big deal. There are states that I know of that have had their money go to places they should not, that Centers for Independent Living should not have gone.

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We, in Indiana, basically preempted that before it even happened here. So that was a good move in this state. Another thing that happened probably five or six years ago, Centers for Independent Living were never included in the General Assembly budget, in the state budget as a line item. We were always-- If we got state money for Centers for Independent Living, the money was discretionary. Then maybe they would pull some funds that they had left over from Social Security reimbursement, from Vocational Rehabilitation. But those dollars could be just as discretionarily offered as they were taken away. So, we got, probably five or six years ago, the first time funding in the state budget for Centers for Independent Living. Now, it's not the complete amount that we get but it is at least a toehold, it's a hold in that state budget.

Another change, you know, and I'm kind of talking about money now because a lot of times, you have to follow the money first to understand how you got where you're going. The relationship with what the feds called a Designated State Unit, that unit that is responsible for Centers for Independent Living, the DSU. Those relationships in Indiana have not always been very good. Every state that gets federal money whether it's directly to Centers or that money that goes to states that could be used for other stuff, Independent Living stuff, every state, to get that money, has to have a federally-approved plan, a State Plan for Independent Living, S-P-I-L's bill, State Plan for Independent Living. That plan is unique, it's federally mandated. That plan is unique because it's-- the State Council for Independent Living, in Indiana it's the-- it's ICOIL, that Council has signature-- the state DSU and the Council both have signature authority over that plan.

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So if the state comes up with a plan and they want to run it through the feds, if it's not signed by the State Council for Independent Living, the feds reject it. Indiana tried that once. It is not a valid plan unless the citizen body signs off on it. How cool is that. How democratic is that. The Council is a majority of people with disabilities. It's perfect for us. And those plans were often in the past battle zones. Centers wanting to grow its network, our network, it's federally mandated, the states do that. States not really recognizing Centers as a priority. Yeah, this whole movement, this whole independent disability rights movement of people saying, this medical model where we're broken into professionals and the experts here to fix this, we shut up, we do what they say. That whole model was replaced with this model of consumer control, the experts are the people who have severe disabilities.

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I'm not sure we were ready to buy that in this state, probably not in a lot of states. So, the state plan would become a battleground. Were leaders of the State Council, a Council I served on a number of years and chaired for three years. Where it would come right down to the wire where we were negotiating, what had to be in that plan and funding for Centers, and withholding our approval and our

signature because the state did not have a plan unless we signed off on it. Some of those negotiations I remember one in particular, Nancy Griffin was in there as a leader of ICOIL, Cary Kelsey was part of the executive committee of ICOIL at that time, myself, it literally came down the last 30 seconds before that meeting was about to be over, when we finally got the things that we needed. So, in Indiana, in the past, in the '90s and probably in the early 2000s, we had a difficult relationship with the state of Indiana.

[00:18:07]

That's not the case now. And we should be proud of that in this state. That relationship, at this point in time, is good. We've got some great people in the DSU -- in Vocational Rehabilitation that we work with Kristy Russell and a number of the folks in state government had been strong supporters. I mean, they drank the Kool-Aid. They understand what this is about. And they know that this is the right way to go. So we've had, for the last number of years, pretty positive relationship with the state and that's a huge difference. You know, before that, there are not only the state plan under Mitch Roob, FSSA, there were some terrible battles that went on. Battles that we literally were producing 150-page documents of documentation of what we were being told and what they were actually doing and the discrepancies that we were getting out of FSSA, published them and distributed them to every member of the General Assembly, pulled in the media from all over the state.

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I mean, those were some pretty hard-fought battles. We're not going through that now. My hope is that in Indiana, we've learned at the political level the value of this model that says, the people you serve are the experts in service. My hope is that we've learned that. We'll see, politics come and go.

JHS: I may have missed it but if you could spell out what ICOIL is and when that started.

DN: Yup. ICOIL stands for the Indiana Council on Independent Living and ICOIL is the acronym. That was-- originally, a State Council was originally required in the enabling legislation in the Rehab Act but it did have a lot of authority. It was an advisory council. And then, as time went on and reauthorizations of the Rehab Act happened, Rehab Act is now part of the workforce development stuff and then incorporated that into that legislation. But it's-- reauthorizations went through every five years, those state Councils have gotten more authority. That signature authority over a state plan, they got. And they got-- State Councils for Independent Living or ICOIL in our case, Indiana Council on Independent Living got more authority, got more specific direction on what they were to do. And-- so that has evolved too through the federal legislation over time.

[00:20:57]

JHS: Great. And obviously, you've been a leader in this, of course, some other people that have shown leadership in the area of Independent Living in the state.

[00:21:07]

DN: Well, Nancy Griffin, a long-time friend and colleague who's not in Centers for Independent Living but was at the Center here in Indianapolis, formally IRCIL. I view Nancy as a leader in the movement. Her husband John Cardwell, I view him as a leader in the movement. Both people who have been around a long time. Al Tolbert with the Center in Southern Indiana in Bedford area, he's a long-time leader and one of the first members of the less powerful ICOIL State Council on Independent Living. He was one of the original members of that Council back in the '80s. So right off the top of my head, I would certainly view those three as being people who have been here through a lot of changes and are still here in some capacity, so.

JHS: Great, excellent. Could you tell us maybe a little story about what things were like in the early days of the Independent Living Center?

DN: Well, back in the '90s, early '90s, if we go back even to the late '80s, the center then IRCIL, now accessABILITY. That didn't exist in the '80s up until the late '80s. And they started as a program of United Cerebral Palsy in the late '80s so even then, they weren't a Center for Independent Living. I think it was '88, '89 something like that when they separated and became a Center. So in the very early days, we had two Centers in the state. We had then IRCIL in 1990, a fairly new center and we had the League then, the Allen-- still, the Allen County League for the Blind at that time, still a Center serving one population for the most part.

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So we had almost no Centers in Indiana. We certainly didn't have a network and we certainly weren't evolved as a network to the point of embracing the philosophy of the disability rights movement and the philosophy of the Independent Living movement. We were committed. We knew where we needed to go. And we knew we weren't there. I guess that's how I would characterize the early days in Indiana. We had virtually no political support which is needed in our-- you know, at least in the Centers for Independent Living movement. It was universally understood that if you're a Center for Independent Living, you had to have group homes which is, of course, absolutely not true. And in fact, if you do, you can't be a Center for Independent Living. So very, very isolated, very much in its infancy.

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We were-- Indiana was a stepchild, almost a stepchild of the National Independent Living Movement. We were so small. We were so new. States around us like Illinois, Wisconsin, Michigan, Ohio, these were all states in the Midwest, part of our region, Region 5 at the time that were very evolved compared to us. And if I had to look at it from a perspective of people in Illinois or Wisconsin, I would probably look at Indiana almost with a sense of pity. That's where we were. So the early days, you had a lot of good hearts and good intention people. You had people coming out of a lot of the great social movements in the '60s and '70s that had come into this movement. Maybe they weren't people with disabilities but they understood the need for social change. And you had people that wanted to see things changed.

[00:25:22]

We were very patriarchal state and society when it came down to people with disabilities. We were very much into the rehab model and the medical model of people with disabilities. We're here to take care of them. That's what we do. And Independent Living was coming out with a voice that was saying, "Yeah, yeah, I don't think that's quite right," "No, that's not how it works." So that's where we started. And it was literally-- and keep in mind that the League got its first Centers for Independent Living money 10 years before that, nine years before that and had functioned as this single disability organization under-- basically, under the federal rules that it was allowed to. It shouldn't been allowed to, but it did. So we were in that spot. I can tell you that when I was looking at-- when my family was looking at a move to Fort Wayne, I got a call from the regional commissioner out of Chicago in the federal Department of Education saying that the federal regulations are going to change, and not allow you to be a single disability organization.

[00:26:37]

And he told me that I work for the organization, Vocational Rehabilitation that the state funded-- that the feds funded. And that the feds' intent was to shut down the League and I might want to think about that twice before going there. So, we were at a stage in the early '90s where the federal tide was turning. And we had to decide, are we going to adapt and grow or are we going to stay the same and probably die. At least in our organization, that's what we were at. So, the federal laws were changing. Our neighbors in the states were growing. We were in our infancy. A lot of us had some connections with people in other states that were doing well. We knew how it should be. Nancy had worked in other states. I had spent time with other Centers.

So we knew where we needed to go. And our big battles in the '90s, were really trying to carve out that niche of legitimacy that we didn't have yet, both at the national and regional level and even within our own state, we didn't have that. And carving that out politically, carving that out with the administration that was in place at the time, that was difficult. You'd win one and lose two. You'd win two and lose one. I mean, it was step forward, step backward, it seemed like for a decade. So, it's difficult.

JHS: There's been so much that we could listen to you [inaudible] of the Independent Living, I don't want to leave out the other two things that you mentioned as topics. But before we move say to vocational rehab probably but that could be our next topic, Jennie had said something about Helen Keller, is that--

DN: Yeah.

JHS: OK, tell us about it.

[00:28:41]

DN: When I went to the League in 1990 as the executive director at that time, I told Jennie-- the truth about new executive directors is this, we only know how to do two things, move stuff and clean stuff. That's all what we know for the most part when we start. And that's what I was doing when I got there. We were moving stuff and cleaning stuff. And in the basement of the facility we were in, we found a box of original documents, original newspaper documents. We found old histories of the organization. And in

that box, some of our history that we had forgotten, the League's founders had brought Helen Keller to Fort Wayne in October of 1949 to challenge the community to start that organization, to start then the Allen County League for the Blind. And after that challenge, one year later, the League incorporated and a year after that got its non-profit status. But we had no idea that our founders had brought Helen Keller to Fort Wayne to do that.

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We had lost that part of our history. But we found all the original newspaper bulletins and the original follow-up articles, all that information was in that box. And they weren't copies. Of course, they weren't making copies back then. These were the original documents. So since then, we've preserved those. We had a history of-- with Community Chest, now United Way that we didn't know about. We found that in that box and we just found a ton-- things that we started in the '90s working with kids with disabilities and getting them included in summer camps for all people with disabilities-- all people, neighborhood kids, kids without disabilities, this getting kids included in these kids' programs. We thought we were cutting edge. When we pulled that box of stuff out, they were doing that in the '50s at the League with kids who are blind, that stuff wasn't new at all. I mean, that stuff was 30 years old, we just forgot that we did, so. We found that all.

JHS: We may have to talk to you about some of those artifacts for our projects that have been really very helpful.

[00:30:54]

DN: We'd love to share those with you. We got ahold of the historical society and preserved them according to their instructions. And I had mentioned that we had yet to digitize them but at least, they're on acid-free paper, they're away from the sunlight there and they're stored away so that they'll be there.

JHS: Excellent.

DN: We'd love to share those with you.

JHS: All right. Or maybe we could try to get our brief idea of what you were doing in voc rehab and what things were like in the employment sector back then.

[00:31:24]

DN: Well, yeah. I went to Vocational Rehabilitation as a counselor for the first time in 1978 maybe, maybe '79, somewhere in there. And I would tell you, I had been working at a rehabilitation facility which was a great experience. But Vocational Rehabilitation was the Cadillac of state employment at that time. I mean, if you work for Department of Education or now Workforce Development, it didn't matter where you were, you wanted to work for Vocational Rehabilitation. It was the Cadillac. That was the positive side of that. Now, probably the downside of that was we were part of that patriarchal system. The folks we serve-- this whole concept of people we serve being customers or consumers of services, they were clients, we were the professionals, which made us the experts.

[00:32:27]

We had money. We had stuff we could do that if they wanted it, they'd better do it our way. That's the way things were. Now, that's probably the downside. You know, back then, another upside was that we did have money. And we did a lot neat stuff. Helping people get associate's degrees and bachelor's degrees in [inaudible]. And then after checking for financial aid, not necessarily loans but grants and things like that, after that was exhausted, we could pay all the tuition, all the books and supplies. You know, I remember helping people start their own businesses, small businesses. Helping folks get surgeries that they needed to get some functioning back. We, I don't believe were wasters of money. But we invested in people with disabilities pretty heavily. That was a positive side.

I think we've seen a couple of positive things go down. I mean, state government across the board seems to be an area where we're losing a lot of talent and a lot of experience. A lot of the veterans, maybe across the board in state government are leaving and we're losing a lot of knowledge with that. So, Vocational Rehabilitation today doesn't pull down full funding from the feds. So there's not as much financial support as we had back then. So those-- the desirability of working that organization, I think it is different than it was several decades ago. The-- our ability to really have an impact through our dollars, that has probably changed and gone down some. On the upside though, I think Vocational Rehabilitation has done a great job of understanding that people with disabilities are to a great degree the expert.

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Now, VR can't violate policy and they can't violate federal regulations and laws in their service. They could still say no because they're not in the business of violating the law. But I think they have a much better understanding that the people they serve are consumers of their services, they are experts on the things that affect their life, and they deserve to have control and choice over those things that affect them. I'm not going to speak for everybody in the '70s but I will tell you, I didn't understand that in the '70s. As a counselor, I did not understand that. And I certainly didn't walk that way. So to their credit--

PH: This has been a great [inaudible] and it's 2:45.

DN: You got to get somebody else in here. [laughter]

[00:35:26]

JHS: -- [inaudible] person after.

[END OF INTERVIEW]