



This transcript from the Indiana Disability History Project is under copyright of The Trustees of Indiana University and may be used with permission. Quotes and excerpts must be cited as follows:

Suellen Jackson-Boner, December 7, 2015 interview 044-MI, transcript, Indiana Disability History Project, Center on Aging and Community, Indiana Institute on Disability and Community, Bloomington, IN, <https://indianadisabilityhistory.org>

**ORAL HISTORY VIDEO INTERVIEW WITH
SUELLEN JACKSON-BONER
DECEMBER 7, 2015
INTERVIEWER: JENNIE TODD
VIDEOGRAPHER: PEGGY HOLTZ
RECORD ID: 044-DO**

SJB: SUELLEN JACKSON-BONER

JT: JENNIE TODD

PH: PEGGY HOLTZ

[00:00:10]

SJB: OK, my name is Suellen Jackson-Boner. I'm from Indianapolis and have always been from Indianapolis. I lived in New York for a very, very short period of time. And I've also lived in North Vernon which also ties in to the Disability Connection with Muscatatuck for-- as a youth director. And I am retired now from 35 years of working for the Governor's Council for People with Disabilities, which I would say is probably one of the most fascinating positions you could ever hold.

JT: Great. So you've been here 35 years in this position. Can you tell me what things were like when you first came? Was there a Council? Did you create the Council? Can you talk about when you first started your position?

[00:00:56]

SJB: It's a pretty rocky history because there was a Council. It was not the Governor's Council for People with Disabilities at the time. It was called the Advisory Council on Developmental Disabilities. And it was housed-- it's had a lot of iterations but it was housed I think, when I first came on board, under the Human Service Coordinating Council I believe. And at that time, it was strictly an advisory body. It did receive funds through the federal, you know, through the federal law of the Developmental Disabilities Assistance and Bill of Rights Act. However, much of the money was siphoned off for-- through other means to the Department of Mental Health that created a vision on developmental disabilities. So, the Council had very little control at that particular time with regard to its destiny and activities. It was very much-- and at that time, it was considered probably more of a compliance body because in order to bring those federal dollars down, there had to be a Council in place and this Council then was under, you know, another governmental agency at the time.

Indiana Disability History Project

Indiana Institute on Disability and Community

1905 North Range Road, Bloomington, IN 47408

indianadisabilityhistory@gmail.com | indianadisabilityhistory.org

[00:02:13]

Then there was a period of time where the Council then moved underneath the Department of Mental Health and it was attached at that-- well, it probably became, you know, it was kind of its own division on the Department of Mental Health, however, it was still an advisory body and it worked very closely with the Developmental Disabilities Division. And again, much of the funding that came through the Council was awarded by the state through the state budget agency process to the Division on Developmental Disabilities. It paid for many of the staff positions and some of the projects that they had created. The Council again was not at that point a very active body. However, over the years, it became a very strong body of people and at some point we were successfully able to retrieve the money that had been going through the Department of Mental Health back to the Council for the Council then to make decisions about funding projects and programs.

And then we also then acquired a staff. We also started-- because of the work that we were doing, we also needed to hire staff to be able to do these different kinds of activities. And so, we then-- we're able then through-- it was a lot of effort to get all that to happen because at that point, the state of Indiana had its eye on how those dollars, how they wanted to spend. And it was being spent not as supplemental but actually to actually run programs and pay for staff. So, it was not as-- I think in the spirit of the law which asks that the money be spent for or allocated toward startups and things like that. But, you know, many of the states, and Indiana was one of those states, that didn't have a lot of access funding to-- for these kinds of services, so they just sort of dipped in wherever they could with federal dollars or whatever dollars they could find to actually support long-- you know, long going, you know, ongoing programming.

[00:04:25]

And so it took some real maneuvering to get the change of heart, for the state to change their heart to allow for these funds to be directed by the Council and the Council will become a strong-- a much stronger body to do-- actually do funding and look at programs and so forth.

JT: OK, very good. Yeah, well, OK. So, you with the Council had done numerous local and statewide advocacy initiatives and projects, would you like to talk about some of those?

[00:05:03]

SJB: Yeah, we've-- What's really been exciting for me is that I think anything you see in Indiana as it relates to disabilities, the Council has had their hand in it some way or another. Some of it has been startup. Some of it has been through, you know, a lot of support, whether it's through, you know, initiatives that were advocacy kinds of initiatives to provide supports. Some of it has been, you know, innovative kinds of things that the Council itself has done in making things happen, again, a lot of advocacy work. And some of the projects that the Council has been involved in over the years, one-- one large one, in the early '80-- 1984, was the supported employment initiative. At that time, supported employment was-- it was just beginning across this country. There were pieces of it going on in Oregon, in Washington State, and some of the states that were much more progressive.

[00:06:05]

I think maybe Virginia was another state where there were leadership that was going on there that created the supported employment notion. Well the developmental disabilities federal-- at the federal level thought employment was and is a very important issue for people with disabilities, particularly for people with development disabilities where jobs just were not plentiful or were not even considered for people with severe disabilities. And so they took on the initiative of supported employment. Well, Indiana got heavily involved in that through the Council. Costa Miller was the chair of the Council at the time. He was the head of the rehab-- Indiana Rehab Facilities, INARF, Indiana National-- I was getting on this and the initials messed up right now. But anyway, he was head of that. He was also chair of the Council so he had a really reason and involvement in terms at the national level.

And so Indiana took that on. The Council kind of became the-- took a leadership role in that and initiated some funding of some projects, some initial projects to show that this was very viable, that people with severe disabilities could actually work, could actually hold a job through the whole notion of supported employment, which is the initiative where you have a job coach. You have somebody who sort of works alongside you in helping you if-- you know, in terms of the-- a job-- there's a job to be done. You have the job but you might need some assistance in terms of learning that job. And so there was a person that was named alongside you to kind of provide that kind of support. Well, it was found out that people with disabilities, particularly severe disabilities could actually hold jobs. And it was a surprise for a lot of folks. And so, that got it off the ground.

[00:08:05]

But one of the most exciting things that happened in that whole initiative, there were several state agencies that had played a significant role in employment for people with disabilities getting employed. That was the Department of Education, Vocational Rehabilitation, the Family and Social Services had funding. There were different funding mechanisms. And what would happen, you know, through the budgetary process is that each state agency would develop their own budget and would, of course, go before the Budgetary Committee, State Budgetary Committee to present those budgets. Oftentimes, what you would see with state agencies, and I'm not certain how true that is today, it may still very well be true, you would see a lot of competition and competing for the same dollars. There was not this, let's get together and try to-- Sorry. Let's get together and try to work together on this. Well, in this particular situation, we had four state agencies come together and support each other's budget for supported employment.

[00:09:14]

So nobody was arguing among themselves. It was everybody came together and so when they went before the budget agency, there was none of this, "I need this money." "You don't get this." "I need these dollars." It was, "Let's all support each other." Which was the first in history to happen. And they supported each other's budget and came out of there with, I think, what do I say, 11 point some odd million dollars together. And this was a mechanism to fund then supported employment initiatives. The Council, by virtue of its federal dollars, we had a lot more flexibility in terms of how we use those dollars as part of that support system. So we funded the mechanism to help get this rolling and off the ground.

And we could do some supports with our dollars that would be different than what education could do supporting of educating students with disabilities with regard to employment and so forth. Voc-rehab could do some follow-along services and placement services.

[00:10:18]

So, there were some gaps, so the Council filled in for those gaps where there were gaps. So through that initiative, we were able to fund a number of programs and projects under supported employment. And we held conferences. We did kind of a strategic way of presenting this. We would-- supported employment was not very well known in terms of what is supported employment. So we held a statewide conference, brought in all the heavy hitters from across the country, and had them present about supported employment to get a lot enthusiasm and rallying point about, "Let's do supported employment, it seems like the right thing to do, it seems like it would work." And then we-- then from the statewide conference, we held regional conferences because not everybody, of course, could go, come to the statewide conference. So we held regional conferences throughout the state, again, presenting information about supported employment. And once we got that presented and people kind of excited about the whole notion about supported employment, that's when we start initiating these projects and programs.

[00:11:25]

And then that's when we, you know, we've developed papers in terms of position papers, fact finding papers and so forth. That was presented to not only policymakers but also to the general public. And that, again, garnered some more support. And then through those efforts is when we were able then to go further and initiate this whole notion of the support for funding for supported employment. So that was one of the first initiatives that we-- that the Council did in terms of some real systems change. Other areas we were heavily involved in was housing. We did a lot in there area of residential services at the time that we were first around in the early '80s. The Council itself, I think, was around early '70s but in a very low-key position. Most people with disabilities went to institutions. There was not much hope for anything else.

[00:12:25]

Parents were told, "That's where your child needed to be." So a lot of people with severe disabilities, not even severe disabilities really, but with disabilities went-- were institutionalized. From the state institutions, there was a movement then to remove them from the state institutions but not to anything much better. They went into nursing homes. Well then there was a court decree saying that states had to get away from that practice of moving people into nursing homes. So Indiana was cited in terms of how many people they had in nursing homes. So there was a movement on to do residential services. So the Council was at the initial starting of looking at group homes and funding of group homes as a way of getting people out of institutions. And that would have been in the '80s. And, of course, there has been a lot of studies since then in terms of group homes was the-- was the next step. But then the whole notion of living in your own home, living in the community in your own home or in an apartment with other people besides people with disabilities and, you know, kind of making decisions on your own then became kind of the next step.

[00:13:42]

And the Council was heavily involved in the funding of a lot of some studies that were done in supported living, as well as funding some projects, some initial projects. And then have gone on since to look at the whole notion of livability, livable communities, visitability, and a home of your own. The Council then started. It was just kind of a natural evolution of-- from institution now to owning your own home or living in your own apartment and making those choices for yourself. And we're still-- The Council is still moving in that direction because there are still lots to be done. So that and then also advocacy work, the Partners in Policymaking. This wasn't our-- The Partners in Policymaking wasn't an initiative that we created. We have to give credit where it's due, Minnesota, Colleen Wieck, who's a very talented, very skillful woman, very visionary, created this whole notion of Partners in Policymaking, of people with disabilities being part of policymaking decisions.

And through her efforts, they created a project called Partners in Policymaking where people with disabilities and family members were provided and were-- well, actually applied for-- to be part of this class for like an eight week or-- which is expanded eight months and once a month, a weekend period where they would come to their capital and learn about disability policy and the issues and then also how to be an advocate. Because many, again, when you're looking at people with disabilities and then when you look back in the '80s and '70s and '60s and where people came from out of institutions, they never have the opportunity or chance to be an advocate or know anything about advocacy. So this was training people how to be advocates to make for systems change. So the Council got involved with that and did a number of those Partners in Policymaking projects over a number of years.

[00:16:08]

And when you look again at history of Indiana, most generally any of the disability rights movement has spun from partners, the graduates from the partners being engaged in those particular project. Many of the project-- many people who graduate from the partners started their own organizations, formulated, excuse me, the independent living centers. A lot of the directors of the independent living centers were Partners in Policymaking graduates. Self-advocate Betty Williams was a Partners in Policymaking graduate. And many of the laws-- [coughs]

PH: Want some water?

SJB: Can I have some water? [coughing]

JT: OK. So we were--

SJB: The partners and in the advocacy work--

JT: -- advocacy work and you were saying-- you were referencing Betty Williams and [inaudible].

SJB: Yeah.

[00:17:04]

PH: -- Policy.

[00:17:05]

SJB: Yeah.

JT: They moved on. So yes, now I was going to ask you about that where some of the advocates from that project went, and that's what we were doing.

SJB: Yeah. Pat Stewart was one of those advocates who formulated, developed the Independent Living Center down in Vincennes. A number of people just went on from there to be very strong advocates, some -- Alan Spaulding from around-- I want to-- I can't think where AI is from, around the Muncie area, around and through that area -- Montpelier. He went on to help develop a laws related, I think, to companion dogs. Many people really got enthused and invigorated about laws because they began to realize they could do something. And they could help make change. And so, some of them really got actively involved with public policy issues in, you know, working with the legislature in getting laws changed and working in with lots of other advocates, you know, developing relationships and partnerships with other advocates in terms of making for change.

[00:18:20]

So, that was one of the things that the Partners in Policymaking did. We also helped funded the Self-Advocates. We were the initial funders when it first started out in Fort Wayne, Indiana in getting that started. And so, there's a lot of things that the Council was at the very forefront in helping to fund or get started and get organized which is really-- I think really exciting when you go down through the years in terms of looking at all the things that the Council has had its hands on and had responsibilities for. It's done a tremendous job. One of the things of course, every year now it puts on this statewide conference which has grown year after year and brought in a lot of people from all over the state and sometimes even neighboring states and sometimes it has attracted beyond the disability community so - and which I think is really exciting that it has looked out beyond the disability community.

Because I think, you know, one of the other things the Council funded of course was when the ADA was initiated-- or before it was initiated, the Council was heavily involved, the staff was heavily involved in working toward organizing people with regard to the Americans with Disabilities Act in helping its-- get it-- in the passage of it. Going throughout the state, Justin Dart came in several times to do hearings and informational pieces and we were very much part of those-- of that with-- you know, with helping to organize people coming-- you know, coming to these forums, these public forums and talking. Then once the ADA did pass, the Council then funded a number of projects to educate people, particularly people with disabilities about what does the ADA mean for you and how do you use it and then also the advocacy work that goes along with that, you just don't, you know, go in like a china-- you know, bull in a china shop to get something done. But how do you-- You know, how do you take a piece of legislation, public policy and how do you get it implemented.

[00:20:33]

So, we did a lot of funding of projects along those lines which was very-- I think, very helpful in terms of getting people with disabilities, you know, on board with what does this new piece of legislation mean, what can we do, what-- you know, what promises it really holds in opening the doors for many things,

not just employment, but for public to access of-- you know, of public buildings and so forth. So, there was a lot of that. We did-- we also did a really exciting initiative called Count Us In. And that was a whole initiative centered around the right to vote, people with disabilities having the right to vote, you know, looking at the statistics, seeing that people with disabilities did not vote, you know, very often and taking a look at that and saying why-- what were some of the reasons. And some of the reasons were that some of the polling places were just not accessible to people, plus the transportation. There's a lot of issues surrounding why people didn't vote.

[00:21:36]

So, we did a whole initiative centering around surveying every polling place in Indiana in real time. And we used people with disabilities to do that. It was not like people-- able-bodied people going out and saying, oh, this doesn't look like it's accessible or not being sure. We actually had people with disabilities going out in teams on-- actually on Election Day and with survey being trained heavily before that and going out. And then we also have them sort of deputized, if you will, through the Secretary of State's office. They had to wear official badges that they, you know, that they were trained and that they had every right to go in to the polling place and do some checking around because otherwise they would have been kicked out. So we had that, we surveyed I think over 5000 some odd polling places.

All in the same day and it had all the data coming in. The Secretary of State's office, we teamed with them. They gave the Council \$60,000 toward this project to work with them. And then we did some follow up in terms of after the survey, you know, showing what places were-- had deficits. And then the Secretary of State's office worked with those polling places. Some of them were moved, some of them didn't-- were able to make changes there on, you know, they're at the site-- particular site they were in. A lot of them moved. So that was a really big initiative and it was very exciting to be a part of that and see part of that. I'm trying to think of other things that we did. More recently, we did a youth leadership-- two summers of youth leadership. Again, one of the things that we found is that a lot of us in this disability community are aging out. We're getting to the point-- we are at retirement age and like many of my colleagues over this past year have retired.

[00:23:41]

And we needed to generate excitement in a new generation of people and the youth is where we need to be. And getting the youth to understand what has come before them, what policies have been passed, what laws have been passed, how that happened, because a lot of it was struggle. There was not-- none of these rights were handed to people with disabilities. People died in the process of getting their rights. Just like any civil rights movement, it's-- it follows the same path in terms of it is a struggle, it's not a picnic. And so, it was to get the youth to understand that, to appreciate that because many of them had lived, you know, were born after the ADA was passed. So it's, you know, again, appreciation for your history but then also getting you engaged and involved. So there is a youth leadership program that has been initiated.

[00:24:42]

The initiative on livable communities, which one that I was super excited about because I think to me that's where the disability community should be. The aged population had been very successful with the whole notion of livability and people-- and as you age, how can you stay in your own home and not have to move into a nursing home or move somewhere that you have no idea where you're, you know, where you've been or what this is about. So the whole notion of livability to me was the next step to me in the evolution of people with disabilities being in an inclusive community. So we did a lot of funding around programs with regard to training people with disabilities, on again, you know, what to expect and how to advocate for living in their community or-- and making sure things are accessible, not only physically accessible but also accessibility in many other ways as well, and also the supports that are needed to maintain your lifestyle in a community.

So we funded a number of programs in that arena, we funded a conference on livability, and then the couple of our past statewide conferences focused on livability and brought in national and international presenters to talk about livability and communities. At that time, there was some excitement about that from mayors and city planners who also then attended that particular conference because they felt there was something at this conference for them and that they can learn from that. And then also having people with disabilities sit beside them and talking to them was I think most useful. I think that whole notion of inclusion has got to go, you know, both ways. You have to have people with disabilities also opening up and saying we want other people besides people with disabilities present at these gatherings so that we have an opportunity to talk to each other, find out about commonalities.

[00:26:54]

And there's a lot of common threads. When you get into livability, you're getting the whole notion of millennials are wanting walkability, they want to be able to walk their communities. They want to have services within their communities. They'd like to have their jobs within the communities. They're looking for mass transportation. They do not want to own cars in particular. There's a whole study out that this is-- that where we're moving. We're moving also to a society that is trading like the bartering kinds of society that used to be where people will barter with regard to jobs. Well, people with disability, this is just a natural-- excuse me, again, [coughs] [pause for drink] if you-- If there's something in particular that you can't do, there might be a neighbor down the street who can do that for you or help you with that. And at the same token, there is something that you can do that might be able to help your neighbor, that they need some assistance.

[00:27:58]

So this whole notion of bartering and being part of this-- what they call-- what is it-- banks-- can't think of the name of it. But it's a time bank where you deposit some time saying, you know, I will be glad to babysit your child and I'll be able to-- be glad to help bake a cake or do whatever, you know, maybe some computer work. And at the same token, maybe you're available to help with, you know, painting some of my house or--

[00:28:33]

JT: Gardening?

SJB: Or gardening or whatever. So that whole notion just to me is a natural for people with disabilities. The whole notion of livability communities, where there are raised gardens, there are community gardens, but there's gardens where everybody can be part of and share in the produce that's being made. There's just a variety of things that I think to me this is the next step in my mind in the whole arena for disabilities because it's happening, whether we take advantage of it or not is another thing. But this whole notion is happening. There are funds that had been made available through the federal government, through banks and what have you with regard to livability. You have communities talking about it and working on it throughout the state of Indiana but also throughout the United States and also in Europe. A lot of this is going on. We can either choose to ignore it or we can be part of it. And I guess I'd rather be part of it. And that's what kind of where I'm standing on that.

[00:29:32]

JT: Great. That's great.

[End of interview]