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**ORAL HISTORY INTERVIEW WITH
NANCY KALINA
FEBRUARY 8, 2013
INTERVIEWER: JENNIE TODD
VIDEOGRAPHER: PEGGY HOLTZ
RECORD ID: 017-DO**

NK: NANCY KALINA

JT: JENNIE TODD

PH: PEGGY HOLTZ

[00:00:10]

JT: Sure. Okay, let's go.

NK: Okay, my name is Nancy Kalina and I am from Bloomington, Indiana. This is where I live. I've lived here since 1995, and I have worked primarily in the area of support employment. I've worked in adult service agencies around the country. I've had the opportunity to work at an agency that was in the process of conversion from group homes to supportive living, and I was the employment director at that place. I actually -- and then I have also had the opportunity to be a consultant or research associate at the Indiana Resource Center for Autism for five years and then from there, went on to work at a high school, local high school, Bloomington High School North where I was the work study coordinator and helped with transition.

JT: We're going to talk a lot about that in a few minutes. The other thing I should tell you is I'm not going to talk to you during this. I'm going to do a lot of nodding my head because she doesn't want to hear me.

[00:01:28]

NK: Well, probably in college. I was wondering around in college and first started majoring in occupational therapy then went to speech pathology, and was really unclear about what I wanted to study. I had an idea having grown up with a disability that I wanted to work with people with disabilities. And I went to an education advisor who said do you know about rehabilitation psychology, which I didn't. And University of Wisconsin Madison had a program in that, so I went to speak to the chair. That seemed more appropriate because I knew I didn't want to teach even though I went on to teaching. Rehabilitation psychology was the program that very few schools had that studied working with adults

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with disabilities. So I did my -- finished by bachJelor's there and did some internships, and then went on to do my masters at Syracuse University. So that's kind of like where I began.

[00:02:31]

JT: Yeah, that's great. So I know you said you kind of finished up working in the schools in a transition program. I want to talk about what school was like, what a typical day for a student was like, a kid with a disability in high school.

NK: Well, you almost have to kind of -- if you want to talk about a typical day for a student with a disability, you almost have to talk about what kind of disability to be honest. Because you have students who are on diploma track, you have students with disabilities who are on honors tracks, and then you have students with disabilities who are on non-diploma track, and their days are vastly different.

JT: Let's talk about students on the certificate track.

[00:03:11]

NK: Okay, so students on the certificate track might -- at the high school that I taught at, would typically either start their day in work study if that is something that the student and the parent wanted the student to study and then they might have -- I mean, it depends on what year the student was. If the student was a freshman they would probably have work study for one block or two blocks, and we were on a block schedule. Then they would probably be in some self-contained classes; self-contained English, self-contained social studies. It's very possible that they were in classes, regular education classes in certain areas depending on the student, what that might be whether that be a typical PE class or choir what have you, typical art class. So that's how their day would be. At North High School we had four classes a day. We had two classes typically then a lunch and then your third and fourth class.

JT: Can you explain what work study is?

[00:04:19]

NK: Sure. Well, work study, when I was running it, was basically the opportunity to learn work skills and then the opportunity to put them in place. So we started off -- as students were young, we helped them learn work skills by basically just having a job. That job might be in the building. It might be volunteering in a place in the community like the Banneker Center or Boys and Girls Club, and there were lots of businesses around town that were very open to offering that. Then as the student got older the student would take on more work study. Of course this had to do with if the parents and if the student, if this was the focus. We often struggled. Some parents really wanted diploma to be the focus and that became a point of contention on some levels in IEP meetings. But if work was the focus and really the goal for the student then the student would take on more and more work study, potentially four blocks, which would be half a day each day and the student -- we would hopefully help the student get paid employment somewhere in a job that they desired, in an area of interest, and that would continue probably post high school.

[00:05:40]

So students worked in a variety of places. They worked for IU. They worked in the dorms. They worked in some of the eating areas around IU. We had students who worked for Solution Tree, which is a publishing company in town. I mean it's a variety of places. Basically, there was just this growth of learning the skills, learning to be on time, clocking in, signing out to the extent of doing your job fully, even without supervision.

JT: I don't know if this is something we need to talk about here, but can you not be on the diploma track and be doing work study at the same time? They're getting a certificate. Oh, so you're saying if they want a diploma that's different than a certificate?

NK: Right.

JT: Okay, so if a parent wants them on a diploma track that is a regular high school diploma, that is not a certificate of completion.

NK: Correct.

[00:06:37]

PH: So yeah, I was thinking go ahead and talk about the other two tracks. You said there would be three different...

NK: Well yeah, because if you have a student who's on -- I don't think I ever saw a student with a disability, but I know they occurred. Students with disabilities who were on honors track -- I never saw those individuals so it was very clear the focus for those individuals was academic. They wanted an honors diploma not a core 40 diploma, and there was really no time for them in all honesty to have work study in their schedules because of what is required for an honors diploma in a state of Indiana, so I never really saw those students, but they certainly exist. I did definitely have students who were on a core 40 diploma or just even a general diploma track, and that would sometimes get sticky. I mean, you know, it -- there's a real desire to achieve the diploma. Certain classes are required so then their work study kind of takes a back seat and so it becomes an odd thing, so it's very possible you could have work study first block and fourth block one day and then third block another day, which doesn't really -- is not conducive to having a job.

[00:08:01]

So that's where things would get tricky. It's like okay, so what's the priority here? And many times the priority is the diploma. I mean we really had to have a conversation about what work study would look like based on the fact that you can't really have a job, you know, at 8:30 in the morning and then go back at 1:00. It just doesn't work out that way. So -- but certainly we had students who were also achieving diploma who had work study where the schedule worked out fine. The schedule is the big issue [laugh] - I mean to be honest. The schedule can be quite tricky.

[00:08:36]

JT: That really is good. So the kids that you've supported and the kids that are in schools today when you're in the high school setting, what's the attitude towards the kids? Do you think it's changed over the years? Do you think it still has a long way to go? What kind of issues do kids face in terms of being included to things like sporting events and band, and proms, and the social scene?

NK: You know, I think it's really individual. I mean I think it depends almost like on the individual kid with a disability, but I also think it depends on the class and the teacher. I think that we have come a long way. I grew up in a school where we had kids with disabilities and the kids with disabilities were treated awful and that was in Ohio. I felt like they were not treated well. I think North does a really nice job, however, I think yes there's still segregation and there's still, you know, those kids, and that -- especially the kids with more severe disabilities. They eat over there or, you know.

I think we've made progress. I don't think every kid is receiving that attention. I think that there are other kids who fit in tremendously. Then you had teachers who didn't necessarily like -- "oh that kid could never be in my class." And certainly I remember fighting with certain teachers. Not fighting, I hate to use that, but certainly the struggle of having to have a conversation with a teacher is it all right if this person signs up for your class.

[00:10:08]

That tells me we have a long way to go. I don't even think it should be a discussion because kids without disabilities are not even having that conversation; they're just filling out their schedule form. There's no conversation. So I think there's a long ways to go.

PH: I was [inaudible]. What kind of training and education do the teachers get? Is there something that's ongoing? Do they get anything?

[00:10:36]

NK: Well, that's my -- it's an interesting -- like if they're looking at inclusion, for example. The model that Bloomington High School North was using when I was there and I was there from 2000 to 2011, was a concept called co-teaching, especially in core courses; English, your History, your Science, Your math. And so what would happen would be you'd have your content teacher; Math, Algebra, Geometry and then you would have a special education teacher there to support people who are on diploma track in those situations. And it was an interesting concept in my mind, but I always felt like -- and I think what I heard from people is that many times the special education teacher felt like the regular ed or the content teacher did not necessarily -- many times, I won't say, you know, across the board, but many times, did not necessarily give attention to the kids who needed assistance in that regard or, you know, even if it was a behavioral concern.

[00:11:46]

It became the special educator's job to, you know, to interact or to teach those six kids. I mean -- and not that they were pulled aside necessarily. But it was an interesting -- so, I think to answer your question about what training do teachers receive, obviously your special education teachers receive special education teaching and their license, but I think general education teachers, from my understanding, at least at Indiana University, are only required to take one class, which is basically Introduction to Disabilities and it's not enough. I have guest lectured in that class and I know that I have kept in touch with some of the kids in those classes and they say it's not enough. It's really not enough when kids walk in their class. I think at this point in time, I do believe, if I'm not mistaken, that if you have a student with autism in your class that you're required to watch a DVD or something like that on your computer, whatever, like it might be one or two, three episodes on autism at this point, which -- I remember because I was teacher of record because we had kind of like caseloads if you will.

And if I had students who were included in other classrooms, I was required to document that the regular teacher had watched these DVDs or whatever and, you know, and so I was required to document that. Now again, did they actually watch it? I didn't have time to necessarily sit down and have them watch it and that didn't necessarily take place, so I don't think it's a lot of training.

JT: I'm going to get back to that towards the end.

[00:13:15]

NK: Sorry if I'm repetitive.

JT: No, no, no. We're going to talk more about that later. No, you're good. Is North -- North has the nice transition program or has the transition program that you were involved in. Do many schools have programs like that in Indiana?

NK: Not to my knowledge.

JT: You need to put that...

NK: Yeah, I don't -- I think North -- actually Monroe County and actually even Edgewood to some extent, Ellettsville, have transition programs in place and they've been in place since, you know, before 2000. And that was something clearly put in place. What I would say is when I was at the Indiana Research Center for Autism and I would travel around to high schools around the state that many state -- many schools don't have something like that in place. I think schools were starting to figure out gee we need to help people get employment experience, but the concept of actually hiring -- like, a work study coordinator and having someone do this full time, I don't think is in place in many schools around the state let alone the country.

[00:14:50]

JT: Is that because of funding or priority? Why do you think, given the success, that it can bring for kids that are leaving school, why isn't it more prevalent?

[00:15:03]

NK: That's a good question. It's a good question of why it's not more prevalent because it is -- obviously, we've shown through research that the more kids work at a younger age with disabilities, that the more successful they will be later in life. Research has shown that over and over again, so the question is why aren't schools putting money into this. I would probably say that either money is -- funding is an issue, but I would also say that it's an interesting thing because I think even in my time period at North High School, it's really, really fascinating. It was really fascinating to watch how the priority is really about the diploma -- or is about college prep. I mean, and so there's a definitely was a feeling that this is the area where we want to gear our money. Now of course, you would have general education teachers who would say special education gets tons of money I mean look at all the one-on-one para educators and things like that.

They would say we were reaping in the money. I'm just not sure that the money is used in the most efficient or effective way in many schools.

JT: And there's the ongoing argument that college isn't for everyone, even those that can go. And some people can't afford it.

NK: Right.

JT: And some people can't get a job once they get out of college.

[00:16:35]

NK: Right.

JT: So it would seem in these economic times that careers, employment, things like that particularly for people that aren't going on to college would be equally important.

NK: Oh, yeah.

JT: But was there discussion?

[00:16:53]

NK: Oh yeah. There was -- I think those conversations came up in staff meetings, the conversations about, you know -- it, you know, with these economic times is that we should be focusing on careers, and we should be focusing on work skills, and we should be focusing on helping people learn these things so they would be ready to go as they left high school. And what's really interesting is I think it was highly driven by parents, to be honest. I mean, I think there's something about achieving that diploma that is all so important or I want my kid to go to college. And the interesting thing is I know I've asked the question many, many times during case conference saying okay so the kid gets a college degree, then what? You know, then what? And it's very possible for someone who might achieve a college degree that they can definitely go out and get a job all by themselves, that's possible, you're still going -- there were certainly kids I know who had certain types of disabilities that they were really going to need to be

supported through college, and they really were going to need support to learn how to obtain and maintain employment.

[00:18:02]

That was -- they were clearly not a priority to the parent. And so again, I think it's about getting that gold medal sometimes and it's very parent driven, I would say, because I think kids kind of want to please their parents, to be honest. I mean -- so I don't know if all the time the kid was that interested in achieving diploma as much as the parent was.

JT: Well, it's a status thing. And it's kind of a little benchmark you mark off, graduated high school.

NK: Right. Right. It's unfortunate that we think that the diploma -- I mean it was kind of nice to have the days when we just had a general diploma and everyone just earned that, you know. And there were a variety of ways to earn that and we had kids in vocational, you know, school and things like that. Because I think college is not for everybody. And we are not training a, you know, fully functioning or, you know, an era of kids that are even ready to go out into the world of work. I mean I even think there are kids without disabilities who could really benefit from learning some skills on how do you work in the workforce because I see kids all the time who are -- I mean from my point of view, don't have skills on showing up on time or calling into work, and, you know, things like that.

JT: They don't know how to work.

[00:19:31]

NK: Okay, yeah, they don't know how to work. Yes.

JT: Was North the school that had the peer tutoring program?

NK: Yes.

JT: Okay. Were you there when they had that?

NK: Oh yeah, it was there -- the peer tutoring program was there before I got there. It was a class. It was not available until you were a sophomore. There were some exceptions. And it -- you know, and I struggled with that concept, you know, because I believe in community building and I believe in bridge building naturally. So the concept that people would take these class -- and you did -- you had a number of people who would take the class because they thought it was going to be easy, and so they didn't put a lot into it. So that happened. I mean, we know that happened. There were definitely some great kids that came out of that. I know that they were expected to read certain articles about transit.

[00:20:25]

JT: Can you explain what it is and how the kids were matched up before we get too deep into...

[00:20:30]

NK: Sure, peer tutoring was basically mostly a class -- it was basically a class that was taught by one of the teachers -- or both teachers actually who taught -- had classes with kids with substantial disabilities. So they were responsible for these kids' curriculum and they were responsible for their grades, as well as being responsible for the kids with severe disabilities. Primarily, actually in the beginning, peer tutors only worked with the kids with substantial disabilities whether they helped them with academic work -- and usually -- I mean, kids took peer tutoring for one period. It was a 90-minute period and they might help them academically. They might help them with an in-school job. They might help them in PE, play along with them whatever they were instructed to do. So yeah -- so they just kind of were supportive people.

And they were supposed to be trained by the teacher or by the para educators. And sometimes peer tutors actually went along to a general ed class with someone. So in other words like, even a kid with a substantial disability who was going to an art class or something like that. The peer tutor might be there to be a -- what's the word I want -- like, a, you know, less intrusive support and someone who might help bridge build within that class.

JT: Did much of the bridge building happen? Were there many natural friendships that came out of this or many people doing things outside of the 90 minutes that...

[00:22:12]

NK: There were some. There were really some amazing stories and they're people who have gone on to study education. They're -- I wouldn't -- and I wouldn't say that was the majority to be honest. I know that they're -- one story that comes to mind was a young man who took one young lady with a disability to prom. And that was -- you know, that was lovely. And actually, I believe he's gone on into the field of disability. So yeah, I think that we had some unique stories and things that went outside that 90 minutes. I would say that was probably not the majority.

JT: And is this something else that's pretty much isolated to North or is this something that you see around the state, the peer tutoring concept?

[00:23:01]

NK: Well, that's a good question. I really don't know. I really don't know. I don't think Bloomington High South has a peer tutoring program, but they might, I'm not sure. I do believe Tri-North tries -- yeah, Tri-North I believe uses peer tutors or has a peer tutoring program. In the little, you know, snippets of the people I know, like, I know a young man who grew up in Munster and is now out of high school. There was no peer tutoring program, but he had a circle of support so his was more natural and obviously far more solid actually, which of course when I walked in and I remember -- of course I came from the Indiana Institute on Disability and Community, going to Bloomington High School North it's like I'm entrenched in great philosophy and progressive thoughts so the concept of having a class just didn't vie well with me.

[00:24:04]

But, you know, it was kind of one of those things you learned to work with and you try to make it as natural as possible, but ultimately it's really not natural, I mean, someone's earning a grade.

JT: Were there many examples of informal or formal circles of support in the school systems that you're involved with?

NK: In Bloomington High School North specifically?

JT: Yes, I guess we'll say there.

NK: We tried because obviously I had been trained to facilitate person centered planning. We tried to bring that to a number of individuals at North. I can't really say that those situations were incredibly successful and I think a good portion of that is, that you didn't have a tremendous amount of parent buy in. Now, you had enough parent buy in to say "Yes we'll do this planning, but I don't want to -- it almost seemed like there were many parents -- I mean the kids who really we thought could benefit from a circle of support were people who, you know, obviously may not have speech or what have you. And -- it -- I think the feeling I got was that the teachers and the para educators or whoever was in this circle was more than happy to do their part and then you'd come to a follow-up meeting or another follow-up meeting, and the thing that the parents were supposed to do or that had signed up to do was not taking place.

[00:25:52]

And I think -- it's interesting because I think schools almost nurture that concept, especially during the school years. Meanwhile I think when kids get into adult services it's a whole different ball game. There's something about putting your kid on a bus starting at age five and the school will take care of it. There is a little bit of that mentality with parents. I mean I think there are some parents, but again I would say probably the minority of parents I've dealt with who really wanted to -- you know, and keep in mind, I worked with kids in high school so you might have parents who are very tired at this point, but you didn't have -- I didn't see a lot of parents were really willing to kind of, you know, plunge through alongside teachers or what have you. I didn't -- we didn't get a lot of that. But I don't know of a few circles of support that have existed in Rensselaer and in Munster that were incredibly successful, but again, you had incredibly strong parents who wanted it, who were more than happy to volunteer, who were more than happy to pull people together and that's really so absolutely instrumental in creating a great circle of support.

JT: Right, well, you can't have circle of support for everyone in the school...

NK: No, no.

[00:27:12]

JT: ...but yes, you do need someone to drive the bus so to speak and you do -- and it needs to be the parent and other people.

[00:27:17]

NK: Right, you can't -- in circles of support you can't -- the teacher can initiate possibly, but I don't really think the teacher should be the person driving the bus -- I mean, in the long run and it really needs to go back to the family, the responsibility.

JT: Or to another champion or something because the teacher just has too many other students.

NK: Exactly and plus the teacher will not be there in following years.

JT: Okay, before we switch to facilitated communication, is there anything else you can think of about support employment, teaching...

PH: Unless you have some other examples.

[00:27:55]

NK: One thing I was just going to mention around transition, which was I -- you know, it's so wonderful that I've been able to work on all sides of the spectrum -- I mean, from residential to education, to adult services. It's so I didn't realize, because I came from the world of adult services, that so many people on the education -- you know, in the area of education are so unfamiliar with the world of adult services. And it is a funding nightmare to be honest. And Kim reminds me often because she never knew about the whole funding issue and the funding issue is very different, obviously, because the state funds education. I actually once proposed a position, that a position be created and in addition to the transition coordinator, which is the person who runs the case conferences, pretty much. That you need someone in the school system who just educates parents, really starting in like possibly earlier than eighth grade -- sixth grade, because I think transition is what now, 14 years old or at the eighth grade conference.

People don't realize it's that whole concept of where the responsibility is. Is that when they -- its entitlement. I mean, that's huge. Is that kids are entitled to a public education. When they leave, there is no entitlement. If you basically don't sign up for vocational rehabilitation, if you don't sign up for going to an adult service -- an adult -- whatever they call it, oh my God -- ARC, no one is going to come looking for you, I mean to be honest. There is no entitlement. There is no one saying, you know, we'll go find you. I actually, when I was at the Indiana Research Center for Autism, dealt with a family in Indianapolis where that was the case. The kid had been home for 11 years. The parents knew nothing. I was like how could you not know I mean, that Noble exists, or. And it was just so shocking to me, but I think that even when you -- what you have in most schools across the state of Indiana -- most.

[00:30:13]

Is that you have special education teachers. Again, the -- they're teachers, they know education, they know IEPs, they know curriculum. You know, they may know some positive behaviors support. They don't know how VR works, vocational rehabilitation. They don't know that when someone's employed [laugh] -- and I mean this is changed, and it changes every year -- every month actually. I mean that's when someone is getting a job vocational rehabilitation will pay for the looking for the job and the

training on the job, but when they move to follow along if you will, like when someone can fade off, they don't realize that funding switches to the Bureau of Developmental Disabilities. They are unaware of the Medicaid waiver or the importance of the Medicaid waiver. Teachers are very unfamiliar with that whole piece. And Kim always used to tell me is that I was in such a unique position because I had that piece because I had it from the time I started my career in Syracuse, or actually in Washington State.

[00:31:22]

And that's such an interesting component that it would be so important for teachers to get and to understand why. And we actually tried. We tried really hard to educate -- Mary Hill and I -- who'd be another interesting person to interview, we tried to meet with elementary teachers in Monroe County just to educate them about the waiver because the waiver list had gotten so long. It was -- I don't know what it is now, but it was like 12 years long. And we were trying to get elementary teachers and even preschool to say get your kid -- get the kid applied now, work with your families. We brought someone from the state to the transition fairs to actually take application right then and there. We had so many people who came to transition fairs -- parents, who we could get interested enough who would come just to fill out that application. But that piece is so important because it's such a change.

I mean, I don't know if I can make that so pronounced, but it is such a change because parents have had, for 12 years, no funding worries on any level. And the kid has been entitled and they've had a school bus. And I mean, transportation goes away. You know, no lunch anymore. I mean, it seems so small, but it's huge, it's really -- it's like all of a sudden the bottom drops out unless you've signed up, or applied, or what have you and been considered eligible.

[00:33:00]

JT: One of the things that -- I mean...

NK: That's huge.

JT: It is huge. In the 80s when I worked with a day service provided one of the things that our VR counselors were supposed to do, is they were supposed to go to -- it was in Martinsville. They were supposed to go to Martinsville High School and meet with every special ed student from the time they were in ninth grade to get a transition plan in place so that by the time they left, high school the parents, like you were saying, had several years to think about it and know their options.

NK: Right.

JT: Well, if you had a good VR counselor he would do that.

[00:33:34]

NK: Right. And your -- some people around the state where they can't even get a VR counselor to come to the school for the senior conference. They are required to be there, if I'm not mistaken, for junior conference, for the junior year conference.

[00:34:47]

JT: Yes, I thought it was not necessarily -- I thought it was a mandate where they had to be involved with kids while they were in high school and I don't know how they've gotten away with it. I was going to ask you if you knew to elaborate about that.

NK: Well, Monroe County again is just wonderful, especially when Donna Wyatt was here, my goodness and Roberta Stafford. Monroe County -- and I think Suzi Rinne had a lot to do with that, Leslie Green from Stone Belt. I mean, they really created a culture at Monroe County, I mean. So people were on board. Betty Anderson, you know, back in the day. And I think that VR was on board. I remember when I first had my job at Stonebelt back in 1993. VR was at my interview, which I thought was really like wow that's really cool actually, that's kind of like surprising. But I actually remember thinking well this must just be the way it is in Indiana, and then -- but it wasn't. It was -- there were states -- or there were schools that would laugh when I would do trainings when I was at The Resource Center for Autism and I would do training on supported employment and people would laugh because they thought you can't get a VR counselor in the school. I mean if you're lucky you can get them there for senior year maybe second semester.

And I don't know how they've gotten away with it, to be honest. Other than the fact that they would probably claim that their caseloads are way too large.

[00:35:10]

JT: Well, and the other point is the teachers aren't required to know this information either.

NK: Exactly, that's the other point.

JT: Push the parents too if the VR counselors are going to come here, here's where the office is, take your student down there and apply for services.

NK: Right. Right. I think that's a big piece. I used to actually, to be honest; I used to actually go with parents. I would actually set up the appointment for them because I just felt like -- you know, it's -- case conferences there's just so much information going on, it's overwhelming for a parent, I can only imagine. I mean, it was second nature for me. It was second nature for the case conference coordinator, but there's a lot of information. And so, I would offer, you know, and probably the majority of the time parents would say "Yeah, if you could set up this appointment that would be great." So I would call Donna Wyatt. I would call Vocational Rehab and I would say give me a date. Then I would actually coordinate with the parent. I many times met the parent there to, you know, to go through the application process. I also did the same thing obviously explaining to parents that they had choice -- they're -- the parents and the student that they had choice on which adult service agency they chose to use, which was a foreign concept.

[00:36:34]

And so, there were many times I went with parents and the student to the various agencies that were around Bloomington who were offering employment support and let them interview. So I facilitated

that process and that's why I felt like there almost needed to be another position. I mean, probably three positions, but someone who basically was focused on educating families around transition and possibly running some -- you know, circles of support when needed, but that would be part of their thing. But I think just educating parents and helping them understand that you're getting used to this system, the educational system, but this system over here is completely different. And the other piece of the puzzle is teachers don't know this stuff. They many not even know that they should be inviting vocational rehab. I remember doing a consultation probably back in the late 90s in Anderson, Indiana.

[00:37:38]

I remember being in consultation, it was in a high school, and I was explaining that vocational rehabilitation should -- it would probably be a good idea to get them involved that these students who had substantial disabilities would move on to an adult service agency blah, blah, blah and the teachers basically had said "Well, we wouldn't involve Vocational Rehabilitation because these kids can't work." And I said -- I mean after my mind blew up, I said "Well, you know what that's not your decision first of all, and it's not your job to decide. I mean, you have no work study program, so -- but it's not your job to make that choice for these individuals. And Vocational Rehabilitation and whatever adult service agency is in your community, that's their responsibility to figure out what kind of job this individual can do, it's not your" -- you know, and so they were making choices and basically selecting not to invite VR based on what they thought the person was capable of, which I wouldn't doubt if that stills happens.

JT: Okay, so are we ready to move on to facilitated communication?

[00:39:18]

NK: Sure.

JT: Okay. Why don't you help me understand what facilitated communication is, how it works, talk about who developed it, what training you went through, and...

[00:39:30]

NK: I have to go through my memory here. I haven't talked about this in so long. Facilitated communication is a type of augmentative communication. I actually don't even know if they're using the terminology facilitated communication these days. I think they might be calling it assisted typing -- I can't remember. I was introduced to facilitated communication back in the early 90s when I was in Syracuse and I working on a federal grant. And at the same -- I just happened to be in the right place at the right time, to be honest. And the federal grant that I was working on was working on an agency that was basically converting shelter employment to community employment, but since our director was tied into the university he was connected to Doug Biklen. Doug Biklen, of course was the first person in the United States who was approached by Rosemary Crossley to bring facilitated communication, I think to the United States.

[00:40:34]

Rosemary Crossley basically invented this -- I was, yes -- in Australia. And she was working with folks who were -- had neuromuscular disorders, primarily people with cerebral palsy, was in the beginning. And I think what she was -- we tend to think of people with cerebral palsy as having neuro motor issues, but that they're perfectly fine mentally. So it made sense for her to find ways for someone with cerebral palsy to communicate. And basically, facilitated communication is you're offering them some type of physical support. And in the beginning -- and I was a beginning person so I'm sure it's changed now. The process was supporting them at their hand or wrist to basically -- the concept was that you were basically not moving them or not guiding them, you are actually resisting their movement and the concept was there is that, especially with people with cerebral palsy or autism, is that you were slowing down their movement.

For some people who don't have really great intentional movement, this allowed them to actually make selections that were purposeful to them. So basically you were pulling back while they were pushing down, and which allowed them to control their movement to a greater degree. So, facilitated communication wasn't always about spelling. It wasn't always -- it could have been just making a choice between two cereals. It was really just about choice making in many, many ways. What it led to was a lot of people, we discovered, appeared to be literate and could not only make selections between chocolate and cookies, or, you know -- colors, but they could move on to saying -- spelling things out. So people began typing and people began expressing themselves and it was very powerful. It was very powerful to have people be able to speak for the very first time or -- and be able to be understood.

[00:42:54]

JT: So there was a lot of talk about this in the early days about were people manipulating those conversations. Whose words were they? Can you talk to that and maybe give some evidence that it was the person's words if you have examples?

NK: I think what's really interesting is, like we were saying earlier, is that there are bad VR counselors, there are good VR counselors. I think there are good facilitators and I think there are bad facilitators so I can't always say that the facilitation was always what I would consider real or accurate. I think if there were people who were trained and who were trained well, and I think -- how you know it's the person, you know, doing the typing is -- I mean, certainly I know I facilitated for people where I would have no idea what the answer would be and it would be accurate. Like what did you have for lunch? And I'd, you know, just met this person and I had no idea the person could write -- whatever, grilled cheese and that would be accurate. It seems like its evidence. There were a lot of research studies that were done, some of them quantitative, some of them done by [inaudible] calculator. A lot of the people in speech pathology had a very tough time with facilitated communication.

[00:44:17]

And I think that on some level they had good reason. On some level they had good reason because I think there were people out there who just kind of tried to pick it up and who were probably guiding. I mean, I know I saw that in my, you know, time period of traveling the country and things like that

because I did a lot of consulting around the facilitated communication. So clearly, there were some people who were not strong facilitators or there were people who were thrown into the role of being a facilitator without proper training just like a general education teacher is thrown into the role of doing inclusion, but they don't have much training. So training is a big piece of it. I think for the people who are actually trained and I think the people who had -- you know, I was just so fortunate. I was there when it really came to the United States. There were tremendous amounts of training and not only was there like a week-long training or what have you, but because we were connected to the university or our project was, we had focus groups.

[00:45:23]

So you know like, you would be working with someone. You'd be introducing facilitated communication to the individuals that you were working with. And so much stuff came up, you know -- I mean, that, you know, training is ongoing, learning is ongoing. And so we were able to bring it back to this group and say what do we do with -- you know like, you know, what do you do in this situation. I think because we got to come back all the time, the training was just so -- it was wonderful because I think training is more than three days. And so I think that for the people who really spent time learning, I think it made sense. I think -- I don't know if I'm answering your question, but I think that there were people, obviously, the process -- when I first started being a facilitator, was to start with your support at the hand or the wrist, but the concept was to move back.

[00:46:26]

I mean obviously, so the person would gain more control over their body. And keep in mind a lot of these people weren't used to controlling their bodies. So we -- but we were asking them to actually try and, you know, use muscles that they hadn't really used purposefully.

JT: Is there anything else you can say about -- you said you don't know if it's called facilitated communication. Do you know if people are -- what are people doing now to facilitate communication?

NK: Well, it's interesting because I know when I came to Indiana I think it's -- there seems to be -- the area of speech pathology, in general, appears to have sometimes want to focus on speech. That's an area of focus, I want to work with young kids, I want to help them say their Rs and their Ts, and things like that. It -- I think sometimes -- I'm not sure. I mean I would be hypothesizing here, but it seems that moving to any type of augmentative device is -- I don't know if they see it as a failure on their part -- or what have you. I mean there are so many kids who are coming up to the high school who had never even been introduced to any type of augmentative communication by the time they were 14. It was astounding to me, I mean, but they were still working on their Ts and their Rs, and their Ss.

[00:47:53]

It just seemed so unfortunate because I know when I brought up facilitated communication at Bloomington High School North it was a very heated discussion. It was very unaccepted. We would have speech pathologists who sat in on team meetings who walked out. And there would be teachers that -- so what you had is you had your team and so, like, for example Mary Hill was a teacher of kids

with substantial disabilities and you'd have a team meeting, and you'd have para educators, you'd have the occupational therapist there, and you'd have the speech pathologist there, then you'd have the work study coordinator. And I would bring up the concept of facilitated communication. And if the speech pathologist walks out, because that is the person who is supposed to provide services to the individual up at the IEP, Mary Hill told me very literally that she did not feel comfortable following through with providing facilitated communication services unless the speech pathologist would be okay with it.

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And so, you know, I couldn't really introduce that very much.

JT: So this might be a future trend in terms of having augmented communication as part of the curriculum of the speech and hearing department.

NK: Oh yes, yeah. I think it means to be huge. I mean, I just think the lack of augmentative communication that I would see around the state when it was at RCA and clearly the lack in Monroe County schools alone is -- there are people out there who have nothing to use, and I think facilitated communication is not the answer for everybody, but it is an option. And -- but I also think that, you know, using other types of talk, you know, or communication devices are options. And they need to be options to speech. And I think that's my frustration with people when I mean we'd have intern students and things like that and they -- I mean would very blankly say, that -- I don't even know if -- there was one augmentative communication class. I'm not sure what it is to this day, but I do remember when Indiana Resource Center for Autism did a workshop around -- or actually no, I don't even think it was Indiana Resource Center for Autism.

[00:50:31]

It was the Facilitated Communication Organization of Indiana that was really almost parent formed and I kind of facilitated it. So there were people who would come together once a month and we brought in Marilyn Chadwick from Syracuse to lead a two-day training. I remember we had fliers and we tried to put up fliers at the department of whatever, the speech department, and they tore them up and they would not support it on any level. And, you know, and of course my guess is they were reading research that basically said facilitated communication is hocus pocus and it's guiding people. And it really opened -- facilitated communication really opened my eyes to the difference between quantitative research and qualitative research.

JT: I don't know that we need this in there, but if people want facilitated communication now or augmentative communication, you have a young child, you have someone in school, what do parents do?

[00:51:39]

NK: Well, what I know people do is that on occasion and it's a pretty rare occasion, is that the speech pathologist from your school system can make a recommendation to -- that the student and the parent go to Crossroads in Indianapolis and they do an assessment, but I do believe that facilitated

communication is not part of that assessment. I don't believe -- or at least it was not during the time period I was at North. I mean it was certainly -- people would come back saying "Well this -- nothing will work" and I'm like -- and I mean of course, you know, one of the reasons it doesn't work is because the person has such limited mobility, which is the beauty of facilitated communication because if you're trained, I mean that's -- we make modifications for people's mobility. I mean, that's the whole point. Yeah -- so that's frustrating. Yeah.

[00:52:36]

JT: That's good.

NK: I hope it's good, I don't know if I'm being...

JT: No that was good.

NK: I'm trying to figure out if we've covered -- we've covered this and how things have changed through disabilities during your tenure. We've covered -- this is about the last thing about the foreseeable future, and training, and education. So I guess the last thing that I want you to kind of think about is people that are coming into this profession. I mean you're one of the younger people we've talked to who...

[00:53:10]

NK: Really?

PH: Yes, you are. So... [multiple voices]

NK: That makes me feel like I've been around so long. Yeah, okay.

JT: But people that are coming into this field, the field of disability, supporting people, trying to improve quality of life whether it's through work, school, just enjoying life, what do they need to know and where do they need to get that knowledge because many of us went to school, and we didn't get the knowledge that taught us about best practices. The sort of people that we all want are people that are creative, that think outside the box. All those things that you don't necessarily learn in school you do informally.

NK: Right.

JT: So what sort of training and education do people that are going into this field need and how do they get it?

[00:54:06]

NK: Oh gosh. What kind of training do people need and how do they get it? That's a tough question. That's a tough question because I agree with you. I mean, I even think people who go through special education training and getting their license, it -- that's actually they obviously have multiple classes on disability, but I think there's still so much. I mean there's so much that's still unaddressed. I mean, one

of the things that's so troublesome to me is that I think a lot of the people who go into the field, but when I think of all the people who go and work for residential support agencies, it's a job. It's a job. It's a part-time job. I can work on the weekend while I'm doing my classes or whatever. It's a job. I think it's the rare situation where it's like there's a person who really connects with the individual with the disability. And that they really -- it's truly about relationships.

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And I don't know how you teach that because I think when you really under -- begin to understand that these are human beings and these are human beings who deserve a higher quality of life, then you seek out best practices or you start inventing your own best practices, you start making sense of what -- you know what I'm saying. And I think people, you know, I know who do best practices and who have really helped to bridge build for people and help do circles of support; I think they understand that on a very deep level. I'm not sure that that comes from training, necessarily -- I mean -- or if it comes from life experience. I mean I'd love to hear your input on that, but it's -- I think -- when I first went into the field I think I went into the field because I had -- I grew up with a disability, but -- and I know that my first job was working with folks with psychiatric disabilities in Washington state and helping them get employment.

[00:56:19]

And I love the concept. I think my master's degree turned me around -- sorry about that. Because it was focused on adult and it was focused on the concept that people with disabilities could absolutely contribute to their communities, which I don't think is a common message. I think that actually the program of rehabilitation psychology or rehabilitation counseling as a degree, was a really important degree to have. Even, I think in special ed, I'm not sure a lot of special education teachers walk out of that thinking that their kids are going to be contributing members of society. And I think that rehabilitation psychology, which unfortunately I think is not doing well across the country. It was not in many schools in the first place; Kent State, Syracuse, University of Wisconsin, I think somewhere in Pennsylvania, but, you know, having Pat Rogan as a professor, to be honest, at Syracuse and learning people first language was huge.

[00:57:24]

And watching my -- you know -- having someone who is questioning you and having someone reading articles that have been published and having you -- teaching you how to read them critically like, can you really trust this -- or do you just trust this article. I mean, having you actually read. I think that whole thing about basically having you think was so imperative and so wonderful because I think it started you -- I think that too many people go through school and don't think. They just ingest what's being given to them. I think those seminar classes I had with Pat Rogan, I'll never forget. I mean the fact that she questioned me constantly was -- you know, it was harassment. No, it wasn't harassment, it was actually. It was wonderful. It was wonderful growth and it got me to think about what was important. And I think that's where it all begins, is figuring out what's important. How do you do that on a major training across country, I have no idea.

[00:58:26]

I think it's person by person. I think you have a good supervisor, you know. I think you have someone who understands that person-centered approach and I think they train their staff. They truly take a part of training their staff and then if you have middle management hopefully they go on. I think it's person by person, but -- and I think life experience is huge.

JT: One of two things that you said, "One is yes there's a huge difference in the person who's going to college and getting a job in a residential facility, but the same people who are saying I want to be a special ed teacher or I want to work at Indiana Institute, they don't have the opportunities that we're talking about. So unless they get informed, unless they get in some work experience..."

NK: Right.

JT: ...I mean, their typical education that leads to this sort of career...

NK: Right.

JT: ...doesn't really currently provide a lot of tools to do a good job. So I guess I'm wondering...

NK: You mean like on the adult service level?

[00:59:34]

JT: Uh-huh, on the adult service level. Well, even on the student level.

NK: Right.

JT: ...I guess one of the things that I wonder about and keep hoping people are going to talk about, is the role of people with disabilities teaching classes...

NK: Yes. Yes.

JT: ...presenting, getting to see them in a different role...

NK: Right.

JT: ...having self-advocates in the school system talking to kids and teachers about what their life's going to be like, having them in the college classes on a more than a guest-speaker basis.

[01:00:07]

NK: Right. I think that's a good point. And to be honest, I think it's really imperative. Obviously we have a long way to [inaudible] -- oh, yes, sorry. Yes, thanks for the reminder. The concept of having people with disabilities teach classes is monumentally imperative because it's -- honestly, in my career, my over 22 years of working with people with disabilities, my best teachers have been people with disabilities whether it's being hit on the head because I was doing something wrong, but honestly they are the best teachers. If you formalize that I know that I've seen people with disabilities in classrooms as guest

speakers and that, I think those classes are so imperative. And I mean, I think kids eat it up. I really do think students eat it up, but then going a step further to say we'd like someone with a disability who's actually teaching or co-teaching a class.

[01:01:10]

I think -- you know, when I think of who I'd like to learn from, Norm Kunc tops the list who has cerebral palsy. Listening to his story is so educational, far more educational than a lot of the professionals that I've, you know, rolled around. But that opportunity, I think that they either need to seize that opportunity or -- you know, and the doors -- we need to open doors for people because I think they're our biggest teachers, they truly are.

JT: So I didn't put those words in your mouth?

NK: No, you actually -- I would totally agree with you. I would totally agree with you. I don't know how to make that happen. I mean I wish I did have, you know, an answer for that, but it's...

JT: That's something that I wish we could figure out how to do.... you said that we need to talk about what is unaddressed in education. When I first started asking you about the training there are so many things that are unaddressed in education, so I don't know if there was something else you were going to -- if you wanted to elaborate on that.

[01:02:30]

NK: I'm wondering what we were talking about.

JT: It was at the very beginning of thinking outside the box, how do we get people to be creative and learn, and do a good job in this field, and really be prepared for a career and maybe that's irrelevant. I just wrote down you said talk about -- or ask you about what is unaddressed in education.

NK: Oh, are you talking about the education or the training of people who want to go into the field? Or are we talking about...

PH: No, I think it was the field.

JT: And maybe that's -- sounds like that's irrelevant at this point.

NK: No it's not irrelevant, I'm just trying to figure out where we were going with that. I know, I've totally gotten congested since I've sat in this room. What -- well, I think there are probably a lot of things that are unaddressed in ed -- I mean in education, but I don't know if that means education like...

[01:03:21]

JT: It was just a follow up question if you had something else you wanted to add. Is there anything else you want to talk about just as a wrap up or anything we didn't talk to you about? You can look over the list and...

[01:03:35]

NK: Well, one thing that comes to mind and maybe others will come to mind, is I think in the world of supportive employment or in the world of adult services and one of the -- when I worked on the federal grant in -- oh, what year was that -- 1990 -- 1990 to two, we were addressing natural supports, which was a big issue hence it lead into bridge building and lead into community building because you were trying to help the individual with the disability no matter what their disability connect with whoever was naturally in that environment whether, that be an employer or whether that be the librarian if they're going to the library, what have you. I don't know where the United States is on that at this point. I know that I was hired by Stonebelt to do that in 1993 and I think I was kind of actually a little ahead of where they wanted to be.

I think what was fascinating about that, which was a learning lesson for me was that, when you use natural supports and you back the employment consultant off the job site and you teach people how to do that, you teach people how to put things in place and obviously a piece of that puzzle is helping a person get a job that they actually enjoy. I mean, that's the like beginning of the puzzle, which is why facilitated communication is so imperative is to help people have a voice. But I think one of the roadblocks I came across and this was back in '93 and I believe this is still an issue is that, when you back the employment consultant off and the person is no longer providing what they call on-site training then adult service agencies cannot bill. You know exactly where it was as going with that. That was a real conundrum when I was at a local adult service agency.

[01:05:44]

It was a very big conundrum because my team, which I was brought in to coordinate a team that would be focused on natural supports and actually utilize facilitated communication, and my team would make very little money. It was really interesting. So it's talking to people about -- okay, how can we think outside the box. And how can we do things differently? And I would have conversations with vocational rehabilitation and say "Well, can we spend more upfront money," because usually you were limited to what kind of money in which part of the process. Can we spend more upfront money in getting to know the person because the more you know the person the better the fit's going to be, right? If you only get to know the person twice, you know, chances are your fit is not going to work in the long run, but if you really spend four to six months getting to know the person and you're not feeling this rush, oh we got a get job, I've got to get a job -- which, the thing is, what a lot of employment consultants feel, then I think -- first of all it's more leisurely.

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Second of all, I think you truly get to know the person. You know more about them than this person lives on the north side of town and this person's in a wheelchair. I mean you -- I think sometimes we don't look at things in a way that makes the most sense. And I think what we try to do is we just try to get them employed because obviously there's a bang for that buck. We get money when the agency gets money as soon as the person gets employed. The agency gets more money when the person is employed for a month. And I think the money is driving how support employment works. I think you might have agencies who say they do natural supports and obviously I would be very critical of this

considering I was on a grant that studied this for three years, but I would say that they're probably not. I mean I know -- you have people who are hanging out on job sites who have no business being there.

[01:07:53]

The person with the disability no longer needs them. And them being in that environment, the only reason they're there, possibly reading a book, is so that the agency can bill. But as long as they're there, the problem with that whole circumstance is that the person's not naturally in that environment and can't naturally engage with ones co-workers or ones customers, or whatever the circumstances is. I mean just having that job coach or employment consultant in the environment alters the environment. And so, I think that's a concern I would have in the area of adult services, is that we've gotten away from how we approach helping people get included in the community. I think we let money drive it and I think that's unfortunate.

[END OF INTERVIEW]