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**ORAL HISTORY VIDEO INTERVIEW WITH
PATRICK SANDY
SEPTEMBER 2016
INTERVIEWER: JENNIE TODD
VIDEOGRAPHER: PEGGY HOLTZ
RECORD ID: 039-DO**

PS: PATRICK SANDY

JT: JENNIE TODD

PH: PEGGY HOLTZ

[00:00:10]

PS: I'm Patrick Sandy. I'm the president and CEO of the Easterseals Crossroads here in Indianapolis. I currently live here in Indianapolis, but I grew up in Kokomo so I'm a long-term Hoosier.

JT: Okay great. Well, Patrick what I'd like to talk to you today about one of the things are the early days of the rehab industry and primarily day services not so much residential services, so if you could talk about the general philosophy of those services, what sorts of services and supports were provided and then what changes in the ways of services have come through your tenure in this field?

[00:00:49]

PS: Okay, so in thinking back about the kinds of services that are available through day programs in the state of Indiana, I'm not going to say exactly how long I go back, but what I'll tell you is that when I first became involved in day services. Most of the day services were delivered at institutions instead of even community-based organizations and those services were really oriented towards I'm going to use the term 'warehousing people' where they were put in a room and basically someone supervised their activity but there weren't a lot of planned activities during the course of the day. It was really more oriented to the television being on and maybe cards and magazines that sort of thing, but not a lot of activities oriented towards trying to help folks be able to explore things about themselves or even learn new skills.

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[00:01:49]

JT: So, fast forward, talk about day services today.

PS: Day services today are evolving. They continue to evolve. They're really oriented towards trying to figure out what each individual wants to achieve, what kinds of interest they have, what sorts of things they'd like to learn about their individual communities, ways that they can be challenged related to, you know, just the lifelong learning process. So, we're not where we need to be, but we made huge improvements. Now I think programs are tailored to individuals. They still are I think more I think more based in an organization than in the community. I think part of that has to do with funding that it is kind of expensive to be able to provide the kinds of supports to have people really participate fully in the community every moment of their day, but we've made a lot of progress so now folks are having the opportunity to be able to direct their own services, be able to make decisions about what they want to participate in and what they don't participate in. They are very community engaged, so everyone that participates in them gets an opportunity to be involved in some capacity in the community that's meaningful to them.

JT: And how do they figure out what might be meaningful to them? How do they go about making decisions?

[00:03:23]

PS: How do they go about making decisions regarding what is meaningful? I think there are a lot of different ways that it has to do with looking at the individual and doing person-centered planning when they first become involved with an organization that provides some kind of day programming and then it's up to the institution to begin to really explore what is meaningful. So, it involves talking to the individual or communicating with them verbally or by watching their behaviors and the things that they're able to express nonverbally. It's about talking to family members. It's about talking to other service providers that may be involved in their lives other people that may not be members of the family, but that are critical to the individual and involved with them and really doing a discovery about those kinds of things that are important, what works what doesn't work, what have they expressed interest in before.

So those are the kinds of approaches that's very person-centered and then a plan is put together that really says these are the things that we really believe re important to the individual. These are the things that we think are going to result in meaningful activity and good learning experiences that match what they're interested in so we begin to develop programs based on that.

PH: Put the [inaudible] to the middle. It's okay to use your hands but when your arms hit the.

PS: Oh, it makes the, okay.

JT: Alright.

PS: I'm a hand talker, so --

PH: Most people are.

[00:04:57]

PS: I'm doing really well at trying to hold. [laughter]

[00:05:00]

JT: And you're doing a very nice job of it [multiple speakers]. [laughing] Describe to me as best you can and you can just pick anyone who comes to mind, a day in the life of someone getting, receiving day services that does not have a job. So what their day might look like.

PS: Okay.

JT: Or their week if that's easier.

PS: So if I'm to think about an individual that we're supporting and what a typical day might look like from them, I have someone in mind. HIPA keeps me from telling you who that is, so you'll have to trust me here. But, they would come to Easterseals Crossroads to begin their day in the morning. Our day program does provide breakfast, so they would be served a breakfast and the breakfast menu is really based on the kinds of things that they like to eat or any diet restrictions that they have and after breakfast, one of our staff would sit down with them and talk about what's going to happen today, what kinds of things they're going to be involved in today. And if there is no concern about that if the individual hasn't changed their mind about something, then we begin. And it might involve going out into the community and going to a volunteer site where they were going to be engaged in some kind of activity. It may be just a sorting activity, it might be you know delivering mail around a small company, it might be just helping to clean the shelves of some other nonprofit that's interested in having volunteers, but it would be an activity that was really designed around them.

[00:06:35]

It would just be them and maybe in some cases one other person, but it may just be them that's involved in that activity. They may spend a couple hours there. Then they would come back to our organization, prepare for lunch, maybe engaged in some exercise. We have a lot of exercise programs that we do downstairs based on individual needs and then after that, they'd eat their lunch. Then they may be engaged in an art activity or some kind of activity that they've expressed interest in. We have a variety of choices for them to be engaged in. And then we're lucky here because we have a great outdoor space for the folks that we provide services to. So the afternoon might be spending some time outside working in the garden area that we have where they're growing vegetables or working in the garden area just hanging out, maybe just talking to other friends that they have down there or maybe even engaged in some kind of a game because we do have some green space where we play games out there too.

And then they come back in, we prepare for their leaving that would involve a staff member talking to them about their day, discussing the kinds of things that they really liked about the day and things that maybe they had trouble with or weren't sure how they felt about, so that might be a very typical day.

JT: And so this day and this week basically the activities that you're [inaudible] the volunteer and all that sort of thing are figured out based on their person centered plan.

[00:08:12]

PS: Yes.

[00:08:12]

JT: That's all setup ahead of time and then you.

PS: Yeah, in terms of how we decide the kinds of things that they're going to be engaged in during the day, it's directed by them and that comes from the persons-centered plan that we've spent a lot of time gathering information on the individual prior to their even being enrolled in our program.

JT: Okay, good. Yeah, we talked to Connie Ferrell at length about persons that are planning, so this will be a nice.

PS: Okay.

JT: Tie-in to that. Let's see. Alright, so we've talked about a lot of the changes that came with services over the years and there's been a big advocacy movement and self-advocates now have a really strong voice and they seem to be more directing of their own plans, people are listening. So I'm hoping you can talk to me about that advocacy movement. What got staff to listen? Because they've always talked but we didn't always listen, so if you can reflect on the advocacy movement and what really got staff to begin to hear and listen to what people were saying instead of that we know best.

[00:09:24]

PS: So when I think back to the advocacy movement that started in the last several years, and the process that that had sort of generated from ground up in terms of trying to get people to listen to folks with disabilities and what they want and what they're interested in, I think of small things that really have made the difference and I'll tell you kind of a quick story. We had an individual with a significant disability who was also a wheelchair user and used a communication device and they had been with our organization for a while primarily receiving services not necessarily in the day program at that time. And one of the services they received had to do with giving them a communication device that would really work better for them and that actually be attached to their wheelchair so it was available to them at all times. So after working with this individual for quite a while, the support person always takes them after the appointment to the McDonalds and gets them something to eat and has been doing this for months and months and the last time they were here when their communication device was actually fitted to their wheelchair and that person took them to McDonalds at the end of the session, for the first time, this person was able to say, "I don't like hamburgers.

[00:10:50]

I want chicken nuggets." Well it had a huge impact on that individual and ultimately on our agency, because he came back and told people of that story and sort of the groundswell internally was we really have to find out what people like. We can't make assumptions and we need to give people the opportunity to tell us that in any way that they can. So, that sort of was nicely synchronized with the whole notion of we really need to listen to people and move away from thinking we're the experts and we know what's best. So we sort of, that was our sort of flag that we carried out in front of us is we started saying, let's actually start trying to figure out how to hear instead of just making decisions about what we think is best.

[00:11:45]

JT: And do you think we're doing a good job with that? When you look across the state of Indiana and you talk to other people in the field, how far do you think we've come and how far do you think we need to go?

PS: So when I think about the kind of job we're doing across the state and being able to really listen to people, we've come a long way. We've come a long way from the 70s when I first got involved in providing services to folks with disabilities. But we still have a long way to go. We really need to figure out how to listen better. We need to figure out a way of funding the time that's necessary to really listen better so that people don't make decisions based on dollars ever. They make decisions on what people need to say and what we need to hear in order to be able to provide the most rewarding and meaningful experience. I mean if I think about a family member that would be attending a day service, I know that I would insist that every opportunity was exhausted to learn about what would make sense for the person that I care about before I'd have them be engaged in any kind of program service. But I also know that would take some time to be able to do that. We've come a long way. We need to go further.

JT: That was really good. Okay.

PH: Excellent job of putting the question in the answer.

PS: Okay. [laughing]

[00:13:23]

JT: Is this working for you?

PS: Yeah.

JT: Okay. Alright. I write these questions and then I kind of adlib. Okay. Alright, Peggy do you think we have enough on the history of rehab and advocacy before I move into supported employment?

PH: Unless he has another story he wants to.

[00:13:45]

PS: No, I mean I can tell you, I could tell you a lot more about the history because when I first got involved in providing services, it was as a student at IU at the center that you work at right now only it was called the Developmental Training Center and the particular project that I worked with was called the Deinstitutionalization Project and we went to Muscatatuck and plucked people off the day ward that these people were just warehoused. I mean, it was shocking even as a student that that's what was happening; that people were in there being warehoused. And we brought them to the Institute and they actually lived there and then were involved in day services while they lived there and we're a bunch of young students, we're doing our best and we were directed by two really smart people, but we just didn't quite get it even then.

[00:14:52]

We were scratching our heads saying, this is wrong. This isn't the right way to do it, but I'm not sure what the right way is. And it was, it was one of the reasons why I decided oh this is what I want to do, because up until that point, that wasn't my focus at IU. So, I think the experience of seeing people in a situation where you realize they have no control, they have no choice, they have no variety, no texture. There's nothing meaningful to the experience for them is life changing. If you're open to that, you look at that and just say this has to change, but how? And as a naïve student, you know, I thought well we just, we have to just do it all differently and luckily at IU we got to try a lot of things and I think we did really begin to understand some of the ways that we needed to listen, but at the same time we weren't dealing with the funding issues and all that that I think complicate it. It's a very complicated puzzle and we're still trying to sort it out.

JT: So how long were you involved in Deinstitutionalization Project, because we have interviewed people about that, so this would be another nice piece to compliment that?

PS: I was involved in the Deinstitutionalization Project for about a year. And then at the end of that became a weekend cottage parent for children with emotional difficulties another program that was going on at the Institute at that time. So during that year I learned a lot. I was the advocate for three different people that I had. I was involved in trying to find community experiences and that was at that time groundbreaking, trying to get somebody to consider having someone from that project work in their store or be able to participate in some way in the community was just so out there in terms of thinking that we really only had during my tenure one person that was pretty successful. In fact, at the end of the project she remained in Bloomington and never returned back to the institution. The other folks did, the other folks went back.

[00:17:24]

JT: That was good.

PH: Do we want to get a little bit about being a cottage parent?

JT: Do you remember that well enough to talk about that?

PS: I can remember some of it but I was only a cottage parent for about well a little bit longer than a summer. We did it during the summer, so.

JT: Okay. I did one of my social work internships with the DTC.

PS: Oh did you?

JT: And I don't remember much about it at all.

PS: I remember the kids. That is what I remember.

[00:17:57]

JT: I had one kid that I related with.

[00:18:00]

PS: Okay.

JT: He was my social history experience and social work experience, but.

PS: We had four kids that were in that particular cottage that I worked with and they all had challenging issues but they were just great kids. I mean they were great kids, but they were issues that I could see the public school certainly wasn't in any kind of position at that time to be able to even understand what to do or how to support them.

JT: Yeah, they're not.

PH: Must have been what Kim Davis talked about that program. Did the kids stay there?

PS: They stayed there, yeah. They stayed there.

JT: This kid there and I remember thinking he was difficult but I was always kind of just surprised that he had to be removed because he didn't seem that difficult or that was the [inaudible], you know, it kind of surprised me [inaudible] is he really that bad?

[00:18:56]

PS: Yeah. I remember ours. We had one female who only communicated in commercial jingles and you couldn't get her to talk, but she could sing a commercial jingle really well and that presented a little bit of a challenge and then another kid that was really-really totally infatuated with the Pontchartrain Bridge and that's all he ever really wanted to talk about and it could create a problem if you didn't want to talk about that.

JT: Well and they didn't have a label for autism back then.

PS: No. No, they didn't and when I think about it, yeah that was probably central to at least three of the four kids we worked with.

JT: Alright, well good you ready to move into supported employment?

PS: Okay, sure.

JT: Okay, what I want to basically hear about this and then I can ask you some more questions that; tell me about the movement, what brought it to Indiana? Who led it, challenges and barriers and then we'll go on to a few more discussions?

[00:20:01]

PS: Okay. I think that the movement was driven by a couple of different things. It was driven in part by families saying, I think I would like my child to have the opportunity to consider working in the community. It was also driven by research that was being done at universities that showed that folks with disabilities could learn to do a variety of things if you use some sort of systematic learning process and I know you're familiar with the whole project and the bicycles and all of that, that was very eye opening, because I

couldn't put the gears together for a bicycle and I don't, you know, don't even have confidence that I could master that at any point so then being able to see how that was done was certainly very inspirational and made people who were involved in the field scratch their head and say, well boy this opens up a whole world of possibility.

[00:21:06]

So, in Indiana I don't think parents drove it. I think it was driven in other states by parents and Indiana actually I feel like and I was there, I feel like parents were very apprehensive about it and we had to really sort of spend a lot of time nurturing parents and getting them to understand this opportunity is a good one and there's a safety net and it will be okay and let's just try it and see what happens and eventually got some brave people that, you know, said yeah I want something different for my child so we'll do this. So that was an interesting process and they brought up some really interesting points that I think really affected the movement, because of some of the problems this particular industry has. I remember some of the concerns that parents had initially was, well I believe you and I trust you, but you may not be here the next time I come here because I've seen a dozen faces like yours during the time I've been involved with this organization and my child's been involved and if you're not here, is anybody else going to understand what happened here and that I do have the safety net?

[00:22:25]

And those kinds of conversations were hard for us to hear because we were full of energy and excitement about this new possibility, but they're right. This is their child's life. There is a lot of turnover in this industry and it was radically different than what we had preached to them for a longtime which is your child is always going to need the safety of this environment and now all of a sudden we're saying let's go out, let's see what's available in the community and it's going to be great things for your young person that you love and so it was a kind of a incongruence of storm between us as people that we're just excited about opportunities for folks with disabilities. The system that was a little bit apprehensive about whether this was a good idea or not because it was going to change everything that we thought was appropriate up to that point, and the families who were saying, yeah I want to believe you but I'm not sure because you may not be here and I don't know that I want my child to be a guinea pig.

JT: Right. So those were some of the challenges. What are some of the current challenges and if you want you can speak to job coaching, DSP, turnover those sorts of things [inaudible]? So what do you see as current challenges still facing supported employment, because as we know there's not near enough employment for people with disabilities?

PS: Right.

[00:24:00]

JT: We're still fighting that battle. We're still looking at you know trying to raise the employment so if you could talk to that that would be helpful.

[00:24:08]

PS: Okay. When I think about the kinds of challenges that exist even today related to being able to utilize supported employment as a great option for folks with disabilities, some of the challenges that existed in the old days still exist those things with parents feeling some sense of apprehension. I mean if you think about it, parents of typically developing children when they graduate from school and they think, oh my god my kid's got to out and find a job. Some of them get a little nervous about what that's going to look like, so it's not unusual that people would be little apprehensive, so that's still there. I think some of the business community has improved in terms of their acceptance of folks with disabilities as a vital part of the workforce, so that's good. But when we talk about folks with significant disabilities who are really, who we're talking about when we talk about supported employment, it's about understanding how long it's going to take for them to be able to master the skills that are involved in doing a job.

It's about figuring out a way to provide the supports they're going to need to be able to continue to be successful without a funding source, because funding has changed. So you have to look at natural supports and then you have to be careful about how you arrange those natural supports because people who might be a good natural support might leave the business and then that can throw things into a little bit of a tailspin and you got to work on that, so it's about figuring that out. It's about helping the employer understand how they can manage this, how important it is for them to really be able to do that for the individual, for their company, for the community, for our diversity as a society or a city that it is really an issue for all of us. Some employers are really open to that, others are a little afraid and that's based on historical experience and all that. So that's a bit of a challenge too.

[00:26:20]

It's about, and I hate to go back to this because you know we've come a long way related to funding, but it is really about figuring out to braid funding together so that we can support every individual in their specific needs in a unique way that is designed for them because the further we get down this road we realize cookie cutter funding really doesn't work because we're all a little bit different. So that's still a challenge that I think we're working on as a profession. Another major challenge is the turnover. Turnover is significant and the reason is because the amount of money that's available to pay for folks to be able to dedicate a career to this is minimal and there are lots of opportunities that are available that are going to pay people more and you can't help but think, yeah, they've got families that they're raising and they need to look at what sort of resources they need to be able to do that.

[00:27:29]

When you look at the skills that are involved and really being able to effectively support individuals with significant disabilities in community settings and build the supports they need to be able to sustain it, it takes a smart person. It takes somebody who really has the ability to learn a variety of skills and carry around a giant tool chest of skills and be able to pull them out at a moment's notice and figure out what's going to work. So you have to have somebody that thinks on their feet, that is a quick thinker. You have to have a politician because they have to be able to talk to people who are maybe not feeling it, you know what I mean? And get them to understand why this is important for them and those skills take a while to develop and when you're really good at it, other people notice while you're out there trying to talk them

into hiring somebody with a disability. The level of skill that you have and the next thing you know, they've got another opportunity, they're moving on to and you have to start over again.

[00:28:34]

So, that's a significant challenge. To do this well, a lot of pieces have to come together.

JT: That was really good because I think that's a key point that many people miss is that there is such a turnover and we are paying people such a minimal amount that the people that are doing this work, if they're good they're promoted and then they're no longer doing this work.

PS: That's right.

JT: They're supervising people who are doing that work.

PS: That's right.

JT: And the people that are needing that support and that work are left behind.

[00:29:05]

PS: Yeah. We've had, we've been lucky here at Easterseals Crossroads for years and years we had a very stable workforce related to folks that were working in the employment area and we sort of did it in a generalist way so everybody knew how to do supported employment and also could do competitive employment based on the consumer's needs and we were fortunate. They were seasoned, they knew what they were doing, they had built a support network among themselves. They kind of knew who was good at what so that if something came up they could go and say, okay this is what I'm dealing with can you give me some ideas? And then with change in vocational rehabilitation's funding mechanism, it and I'm not judging whether or not that change was needed, in fact I'm going to go out so far as to say it probably was because things weren't working everywhere the way they should have, but that funding change resulted in a lot more of a process where it took a lot more time to document everything.

It took a lot more time to assemble all the information that VR counselors would want; the discovery process was strongly encouraged. Our folks were doing the discovery process before, but they weren't used to documenting it in such a way that it required now, we had half of our employment staff leave within the first year and most of them said the reason I'm leaving is this is just, it's just too much trying to sort this out and how to do it well is too much. I love working with the people, but all of this stuff is just no fun and we're building it backup. We had some you know long-termers stay and now they're getting it. You know, it takes a while to get into the sync of a system and how to make it work, how to actualize it from a plan to what you're really doing. So we're coming back from it, but that created a challenge too.

JT: That's really good. Do we want more on employment? Because I want to talk to him if we; how are we doing on time?

[00:31:12]

PH: About five after ten.

[00:31:14]

JT: Okay, but I want to talk to him still about potentially late life issues or retirement or.

PH: I mean we're going to get other pieces of employment. We have some, so I mean we could always come back once we get some other areas.

JT: Okay. Anything else you want to say about; well I did want to ask you about Employment First. That's something that we haven't talked anyone about.

PS: Okay.

JT: Can you talk about the Employment First movements and how that's a little different?

[00:31:43]

PS: Yeah, when I think about Employment First and what's happening now related to that, I think about how there are so many players that have to be convinced here that that this is a good thing and they need to be convinced before they're mandated. If that makes any sense, because if you're trying to tell somebody they're going to do something before you spent the time explaining all the reasons why it's beneficial to do that so that they can make that part of their DNA you get resistance that's unnecessary. So when I look at Employment First now and some of the things that are happening related to [inaudible] and Employment First, I think that sheltered programs for example and the pipeline that's being cutoff of kids that are moving from high school programs directly into sheltered workshops that we're getting a lot of resistance and I think part of the resistance is because schools are not convinced that it's the right thing to do.

We haven't taken the time to really educate those people who are operating that pipeline as to why that needs to come down to a trickle and maybe even stop. We haven't taken time to really help families understand why it's important that options for community-based employment, options for participation in the community are so vitally important to their child and how that can be done in a way that helps the child continue to grow and helps the community continue to grow and provides for a better life experience for everybody that's involved. I believe that if we can get everybody connected in the educational process so that they're all working towards the same thing and understand the reason behind it, the Employment First movement is going to be successful, but that's going to take some time.

[00:33:49]

JT: One of the things that I recently heard about and I looked it up and it sounds like it's been around for a longtime, but VR is now funding what's called a discovery phase in terms of helping people be able to retain a job, to get a better job match because you're spending that one on one time coming up with some themes and figuring out what really makes sense for the person in terms of a career. Can you talk about that and if that's been successful and people are really utilizing that time to do this and if it's, it sounds really good, but is it true and do you really see people spending the 40 to 60 hours that I understand that is a lot of this discovery phase?

[00:34:32]

PS: Yeah. When I talked earlier about Vocational Rehabilitation and some of the things that they changed related to their new process, one of the big things was this whole piece of discovery and they added discovery because they felt that the information that's available regarding the success of consumers and support unemployment seem to be dependent on how well you really discovered what it's going to take to have a good match. A good match related to the environment, a good match related to the skillset, to the supports that are available, to the area of the community, to whether or not they get to wear a uniform, to any variety of things. And I think we've known that for a longtime that really is the origin of person-centered planning is taking the time to do all that. And I think some agencies around the state were really engaged in doing discovery as part of the process that they would engage in and trying to find an employment scenario.

Those are the ones that I think were more successful. I'm glad that now VR has said, let's just build it into the system and let's give you a certain number of hours to be able to really dig deep about what's going to work for this individual, not just about the skills but their life and all the pieces. We all do that. When we look at a job, we take the time to figure out, okay is this going to work with my schedule, with my kids, with my husband, with transportation, with the environment I like, the culture. So it only makes sense, right? The problem is that when you make that shift and you say this is what we want you do now, you have to really spend a lot of time teaching people what that looks like. How do I really do that? And there's a lot of information out there about methods that can be used and I think that's great because I don't think the same method can work for anybody, you got to take the time to be able to find it.

[00:36:39]

I believe now that we're a year into it, a little bit more than a year into it, people are figuring it out and people are doing a better job of really being able to employ discovery as part of the process, but initially, it was just a little bit foreign and we had a little trouble being able to get the information out about how to do it and the options that you might have to do it before we said, you're going to do it.

JT: That's good. Yeah, it's nice that it's all kind of tying back into the persons that are planning.

PS: Yeah. Looking at individuals.

JT: I wish we weren't doing an interview because I want to talk. [laughing] I [inaudible] the conversation now, but yeah I mean it is so, to me it's just so much common sense. I mean it's the work we did in Martinsville 30 years ago.

PS: Yeah.

JT: And we're still banging on the door saying.

PS: Right.

[00:37:35]

JT: Hey are you listening?

[00:37:36]

PS: Yeah, yeah. But the door's a -- now we can stick our head in and say, wait.

JT: Right, right. That's stuff we've been doing for 30-40 years, but that's; so, I'm glad to hear that and it is interesting in talking to people that are trying to do this work and I do a lot of work with LifeDesigns and Suzi and so it's just such a struggle and you're thinking you're still thinking why is this so hard? But it is. I mean people figuring out how to use discovery is really hard.

PS: It is.

JT: Because it isn't a natural thing, particularly if they've been doing this work for a while, they are so programmed to do, you know, the things that they know are their structured job and discovery is more exploratory and more creative.

PS: Well.

JT: Some people are uncomfortable with that.

[00:38:24]

PS: They are and also, you know, this all comes back to systems and I know there have to be systems that sort of you use as your guideline as you go through things, but when you think about the system for funding that was in place before this one, it was performance-based. So really the motivation there, just by the nature of the system itself was, let's get through this as quickly as we can, let's figure out what's going to work and get the person into a job because we don't get paid until they're working and that sounds cold and calculated that it has to be about money, but in fact, we can't keep the doors open if we don't get paid. So people are driven not so much to what needs to be done for that individual in that process, they are more driven by let's reach an outcome that's going to result in a reimbursement so we can work with more people. That's why I think it was important that the system change in terms of how they're funding things, but at the same time, you can't create a whole new paradigm and then just expect that overnight people are going to understand it, by into it, appreciate it, understand that the advantage that it really gives you as a provider to be able to do a better job because the mindset is still there of, I got to get this through, this person through if I get them through than I'll have another person I can work with and I need to be paying attention to this because the doors need stay open.

So I don't know what the answer is, but we can't constantly be worried about are we going to achieve enough success financially to be able to afford us to continue to achieve success with individuals.

JT: And this is a good first step to really focus on the individual instead of the outcome, because the outcome is going to be a natural outcome if you do the discovery correctly.

[00:40:25]

PS: Yes yeah take the time to do it and get the skills so that you can do it.

[00:40:30]

JT: So what do you think is the biggest challenge facing people with disabilities today? You know, and if you're looking towards the future what sorts of challenges, new things do they have to look forward to in terms of just what they're going to get? How do you see lives for people with disabilities down the road?

PS: Well that's a great question. When I think about what the lives of persons that we support, folks with disabilities might look like in the future and I've got to give that some thought because I can tell you what I'd like them to look like and that's the picture that I keep trying to move towards in terms of my professional goals, but it's a life where they are included in the community in capacities that they are interested in being included in the community in and where they have options for jobs that pay them living wages and offer them opportunities to make choices about things they want to do in their lives. That they have nonobtrusive supports to be able to do that and that includes people that care about them in addition to paid service providers.

That the industry has figured out how to fund things so that it matches the needs of the individual and as a person, as a person, a singular person instead of the needs of the population if that makes sense. We need to look at each individual instead of just putting them in a category and saying, well this is what this category needs because most the people that I've known in my life that I care about the most don't fit in any category at all. I hope for a future where we have quality transportation that's available for folks with disabilities because that is certainly key to their being able to participate, where we have supports for them to be engaged in recreational and educational kinds of activities that are darn near invisible and that the community becomes so accustomed to those things that it's incidental.

[00:43:03]

It's the same as, oh that person wears glasses. That we get to a point where every person is embraced for the contribution that they can make in their life for their community and the people that they care about and for themselves. That's what I'd like to see. And I think that's what drives our industry is they're, I'm one of thousands of people that want to see that kind of community that thinks that that kind of future for folks with disabilities is the best future for everyone not just the people with disabilities.

JT: And the next question I want to ask is even harder and I don't know if you can even answer it, it's basically well it's two parts; is how do we get people that care about these people in their life, you know, the people that we're supporting and you talked about you want people that are paid and nonpaid to care about them, so how do we get people that aren't paid to care about a person and then secondly, what's keeping us from this vision that we all want? So I don't know if you can even answer them, the same question or.

PS: Yeah.

[00:44:13]

JT: Even have an answer for it, but that, you know so what's keeping us from that and then how do we get people that are nonpaid to care about someone they kind of tie together?

[00:44:26]

PS: Yeah. When I think about the dilemma that I think is created by my picture of the future that includes people who are unpaid supporting folks with disabilities, I struggle a little bit when I think about holistically. It's a really good idea and I think it can happen much like I know members of faith communities will step forward and support other members of their community without expecting anything in exchange for long periods of time because it's something they value. It's something that's meaningful to them and because I believe they get as much from that exchange as the person who needs the support. So when I look at it that way, I think well it shouldn't be that difficult because that's not that unusual, people are that way. I think we're kind of built that way. But the problem is evil exists in the world, so there are people that are out there that will take advantage of others.

So I've got this dilemma that I think about of being able to really reach out to individuals to think of this as their opportunity to be involved in something meaningful and their opportunity to contribute in some way and when I think about it personally I think about my retirement which is not, you know, that far off that that's something that I think I'd really like to do in my retirement is to be engaged with some of the people that I've known for years that have disabilities as a support for them and I've learned about them enough that I think I could really be able to do that. But how do you vet these nonpaid supports in way that you can make sure that the person with a disability is really receiving a service that isn't capitalizing on their disability in some way, in a negative way? So that's kind of my dilemma when I think about it, we have to have some means of being able to have people come forward express an interest in being able to do that and then a way of being able to determine, you know, is there a secondary motivation here?

[00:46:42]

No. Then let's move them forward and begin the process of getting to know somebody so that you can provide that support. So it makes my head hurt to think about how do it, but I think there's a way and I think there are people out there that want to do that.

JT: And do you think as people are more engaged in volunteer opportunities and employment and exercise classes at the Y and they have more exposure to typical people doing things that are enjoyable to them and there's common interest, that some of that some of that natural friendship will occur, we just need to figure out a way to be able to fund, to place people in those sorts of environments more frequently than we're currently doing. Does that play into it too?

[00:47:31]

PS: It, yeah I think another way of considering it is as we move forward and folks become more involved in their communities in a variety of ways, recreationally, educationally, so on and so forth continued adult education, participating in some program that's available at the art's center or whatever that we do setup the possibility for folks being able to establish personal relationships with other people who have a like interest, I mean that's what all relationships are built on right, like interests? And that's the most ideal scenario. But sort of a primer to that, is that we have to get folks that exist in those environments to be comfortable with the fact that individuals with disabilities are in fact potential candidates for friendship. I think younger people are definitely in a better position than folks who are maybe in their 40s and above and

that has to do with the fact that I think kids with disabilities are being more and more involved in meaningful activities in school and in educational opportunities.

[00:48:41]

So I know when I think about my own children, they're more likely to go up and talk to somebody that has a disability in any kind of environment than I would have been prior to going into this field and that's because they're comfort level is just there, it's there because of their range of experience, so I think ultimately that will happen, but it's a matter of working with the folks who maybe didn't have the experience of being around folks with disabilities to learn that a friendship is a friendship.

JT: Okay, let's talk about another topic.

PH: Well, we probably have about a half-an-hour because you need to leave at 11.

PS: I do.

PH: We haven't had him sign the papers yet have we?

JT: Yeah, no it will just take a minute. Alright, so just quickly the last couple things before we talk about Steve are -- you support people that are getting older, you know, you support people that typically would be looking at retirement or life issues that have friends and family members that are going through serious health crisis, some are dying. So how do you support people when you start to think about having a person-centered life their entire life to think about these end of life or aging out of typical programs, you know, what sort of support is available?

[00:50:06]

PS: Okay. Can you just run through that question again because I kind of lost somewhere and.

JT: Yeah, [multiple speakers], and part of it with you because you were able to just talk for such long periods which is easier.

PS: Okay.

JT: Because I try to give you a lot of information so that you can pick and choose.

PS: Okay.

[00:50:24]

JT: But one of the things that we're realizing is that we've been asked from time to time to come setup a senior program which we don't want to do within an agency. So when you think about people that are getting older, they don't want to come day services anymore, they want to stay home or they want to be more active with their family or whatever they want to do as people age, what sorts of things are you guys doing or that you think are happening around the state to help people prepare for a retirement per se, and then as people get older, there's lot of choices that we make towards the end of our life? You know, what sorts of choices that we are making and research shows there's not a lot of support in this and I'm curious if

people are dealing with that or they're starting to think about, oh my gosh this is happening we have a lot of baby boomers that we're supporting; what should we be doing? So anything you want to talk about in that area is fine.

[00:51:26]

There's not a specific question, but that's the sort of thing that I've been interested in learning about.

PS: Okay.

JT: So you pick and choose.

PS: Alright. One of the struggles that I didn't talk about earlier that I think is facing the industry related to supporting folks with disabilities, is what do we do when people reach the age where they might typically retire and where their life will change as a result of that? I know that for example when I plan on retiring, that I won't be coming here every day, but I'm already thinking about what it is that I want to do, what do I want to participate in, how am I going to make sure that I continue to stay engaged active, relevant, participatory. And I don't think we do a great job for folks with disabilities in looking at what their future is going to look like. Part of that is because, again, a funding issue. I don't think it makes good sense to fund some sort of congregate setting that everybody goes to and gets dropped off because they're old and sick and might be dying.

[00:52:41]

I mean, that doesn't sound at all attractive to me. It sounds a lot like some nursing homes I've been in and I don't want to go there. There's not an option for funding somebody unless they're engaged in something that you can describe programmatically and since it looks different for everybody, I'm not really sure how we do that. Here, at Easter Seals, we don't have any kind of residential programming so I think part of it does happen from that perspective if they're participating in some sort of a residential program. That there needs to be planning done there and then programs or designing of a lifestyle that they would be participating at that point needs to happen from that center. Here, we're serving them through some kind of a day program that involves community involvement, but when they get to the point where they no longer think that's a good fit, all we can do is pass off ideas to family members.

[00:53:47]

And frequently family members are not in a position where they can actively engage or dedicate a great deal of time to it, so I'm afraid what happens is that people end up sort of being warehoused again, maybe in, maybe at somebody's house, maybe in a nursing home, maybe in some other environment. I don't think it's unique to folks with disabilities. I think it's a struggle that we deal with as a society. What do we do with our senior population? How do we make it so they continue to be involved and how can we support them in making life choices at the end of their lives? So, it's maybe something we can work on together. Folks with, that are typically developing and folks with disabilities so we can figure out a way of improving that picture.

[00:54:37]

JT: That was good. Okay, we will stop there and talk about Steve, but I think this is important to just have because this is a future trend.

PS: Yeah.

JT: You know, this is something that down the road we look at what our field's going to look like it's going to be full of aging [brief laughter].

PS: It is. It is. I'll be one of them.

JT: Alright, are you ready to talk about Steve?

PS: I can try.

JT: Alright, [inaudible] patient. Alright, well let's just start with Steve who was your dear friend, dear friend of mine and many; can you share his contribution, his gifts to the field from stories about Steve?

PS: Okay.

[00:55:28]

JT: Because he is not here to brag on himself.

PS: Right.

JT: And we won't cry.

PS: Maybe.

JT: Yeah, [inaudible] I'm already going to cry.

PS: Yeah. One of the people that I believe strongly has been very influential in terms of services in the state of Indiana is somebody that was also a very-very dear friend of mine, Steve Savage. And Steve was involved in the industry as long as I was. He got involved in the industry when he was in college and was involved in some capacity his entire career working with children or adults, but always working with folks with special needs. I think when I think about what he brought, first of all, he brought the Savage enthusiasm to the industry. And by that I mean he was just full of energy and didn't take no for an answer. He was just one of these people that could push things forward and he did it in a way where he would make people laugh, he'd engage people as friends.

[00:56:42]

He was very good at being able to find some commonality very quickly with just about anybody and then use that to his advantage and being able to push forward whatever his mission was and his mission was very much like what I would describe as the future for folks with disabilities that they are actively involved in the community and it's really their disabilities relatively insignificant in terms of relationships and participation. He had his finger in a lot of stuff too, really. He was never satisfied with just one thing that

he was working on so he might be really focused on transition services for folks at the same time he was very focused on employment services for folks, at the same time he was focused on developing information related to the history of services with disabilities in an effort to make sure that it never happened again. So, he built what he did around his passion for people and his love for people in general. And it just carried over to everyone which included folks with disabilities.

[00:57:57]

JT: Yeah. I had some fun projects with him and it was always fun. So how would you say, and if you can think of stories about Steve that would be great too; what would you say how is he remembered? You know, when people think of Steve and his work, you've talked about some of that, but if you have any specific stories or --around how he's remembered or some of his accomplishments.

PS: I can do that. Just give me a second. How I remember Steve Savage is first of all as probably my best friend in the world. To be with him was always an adventure because he just really liked to, he was drawn to things that were a little bit different, a little bit out of round, you know, that's the sort of thing that really kind of made life exciting for him. So I know they were many times that he and I worked on training programs that we would deliver to folks working in the field and his focus was always we can't just train them, it has to be fun. They're only going to remember this if it's fun, if it's interesting, if there's a way for them to participate, if there's a funny story to tell at the end or a sad story to tell then they're going to take it home and they're going to remember it and they're going to tell other people.

[00:59:30]

So, one of his unique characteristics was we'd put together the program and then we'd go back through it and say what can we do to make this fun? What can we do to get people involved? So a great example of that was one of the training programs that we put together was specifically designed to help people find humor in the workplace. So the program was not necessarily about what you would think were typical skills that people would need to really be engaged in this industry. It was really focused on reviving them because Steve understood that this was an industry that takes a lot of energy and it's very stressful. And so this was a coping skill that he thought was really important so we put together this training program just based on what kinds of fun things could we do that would help people be able to laugh about what they're doing, see the humor in some of the problems that they were facing.

Be able to make meetings more interesting, get people to work together as a team, think about different ways of resolving conflict in fun ways and it was such a successful training program that we did that for years people kept requesting it. We'd do it over and over again and we kept changing it up because Steve also wanted to make sure there has to be, it has to be authentic and new every time, so got to do it a little bit different so that we're happy about doing it. So, that was a particular story that I can think about with Steve related to how he wanted to participate in this industry. I'm going to stop until the beep stops.

JT: That was good.

[01:01:20]

PS: I'm not sure what that is.

[01:01:24]

JT: Fire drill?

PS: I don't know. I hope someone pays attention to it, yeah. I have a feeling it was the storm radio but I'm not sure. Okay, what else can I tell you about him? I can tell you lots of stories, but some of them I'm not sure you would want to have on tape.

[Laughter]

JT: Yeah.

PS: Yeah.

PH: How did you two meet?

[01:01:49]

PS: Steve and I? It's interesting, Steve and I went to college at the same time. He was a year older than me so he was there before I was. I'm sure that we met many times at the School of Education. I know we probably ran into each other many times at Bear's Place across the street because I spent time there and I know he did. We knew a lot of the same people. We had some friends in common, but we never actually met until years later when we were both working for organizations that were engaged in supported employment and we were one of; he worked for one of and I worked for one of the five organizations that first decided that they were going to model supported employment for the state of Indiana. And we were pulled together by a couple of people at the state who were trying to organize a support team for supported employment growth in Indiana. And it was Steve Savage, Suzi Rinne, Pat Sellman, and myself and I think there was somebody else involved but they weren't involved for very long so I can't remember their name and we met to talk about what were we finding that was difficult, what were some of the challenges, how were we supporting consumers and families in this process, what successes had we'd achieved, how did we go about achieving those successes so that we had a way of being able to provide information to other organizations that might be interested in exploring this as an option for their consumers from people here in Indiana that were actually doing it.

[01:03:33]

So that's how we met when we were pulled together for that sort of project. And then out of that, Steve and Suzi and myself and Pat Sellman went to MSU for a train the trainer program on trying to develop means of supporting organizations and individuals who were interested in becoming more engaged in supported employment. And we jelled as a group. It's like something happened that was kind of magic because I remained very close friends with all the individuals that were involved in that at the very beginning and we did that training program for 25 years. In fact, we decided that we would stop doing that program and that we it was going to be easier to turn that over to the Institute to continue to operate because both of, all of us were either CEOs in organizations or were considering retiring in the near future and it seemed like maybe we should step back and let the Institute really provide that technical assistance, maybe not in the same way but figure out how to do it best right now.

[01:04:45]

We made that decision. We stopped providing. We did the last training in December and Steve died in February. So, it seemed like somehow he had some information that we didn't have about how much time he had left.

JT: Yeah. That was really good. Anything else you want to say and I know it's hard. Like you say, there's so much and then what do you say?

PS: Yeah. I, probably one of the gifts that Steve gave to the state of Indiana and they probably don't even recognize it in terms of supported employment, was that he was an incredible mouthpiece for what to do, how to do it, why to do it, and how much fun it is to do it. And to frame it that way for people that are just coming in to the industry, is an absolute gift because you don't have people that are just taking this as a job, you have people who might have taken it as a job but then have had the opportunity to meet somebody who said, boy is this fun, is this exciting. You're going to be able to do such cool things and you're going to make a difference and do it in a genuine way that you know people can tell when somethings genuine and when it's not; in a genuine way that people are drawn to.

I've never in my life met anybody that could do it like he could and that could inspire people the way that he did it.

[01:06:29]

JT: Alright, well. Stretch and take a little break [brief laughter].

PS: Okay.

JT: Is there anything else that you can think of that, you know, you didn't talk enough about or you'd like to say or a personal story you have or a highlight from your career? Anything else you want to say?

[01:06:57]

PS: A little, there's a little story I can tell about someone that I worked with. Probably one of the experiences that I had early on in working with supported employment was with an individual who his means of communication was through, was nonverbal so it was through his reactions to things or you could tell when something made him happy just by the way he behaved or when something wasn't a good fit you could tell. And I remember sitting down with his mother and he was probably at that time maybe in his early 40s and his mother was in her late 80s and I sat down with her to try and tell her why I thought supported employment would really be a good thing for her son and why I thought moving out of the shelter workshop which is what he had been in all his life was going to be a great thing. And I remember her having a lot of apprehension about it and I was probably, I probably met with her for two hours while she talked through all of her apprehension and then at the end, she said "Well, okay we can try it as long as you promise me that if it doesn't work out there's not going to be a problem being able to return to where he's at because he loves what he's doing."

[01:08:20]

And my response was, of course absolutely he can return here, but I think what he loves is working and it doesn't have to be here, but we'll check it out and see. So we did end up finding him a job in the community and it took a while, because you know communication issues and all of that, but we did work it out. We found a job that we thought would be a really good match for him and he started working. The employer was really supportive and things went super well and within six months the employer was saying, you know what I don't know how we did what we do before he was here. He's such a great addition to the team. Everybody here loves him. I'm not even sure we need you to come back anymore, because we know him. We figured this out and we know what kinds of supports that he needs to be able to continue to be successful. And it was like, yes I mean that's exactly what you want to strive for and then I had a case conference where he came in and his mother came in and I remember her saying to me, "When he was born, my physician said to me put him in an institution right now, go home and tell your family and friends that the baby died in childbirth.

[01:09:42]

That's what's going to be best for you and best for him. He will never recognize a ball let alone be able to play with it." And look what he's doing now." And I still remember that conversation so clearly almost verbatim because it was like validation that this is absolutely the right thing to do and that this made such a change in his life and in the life of his mother. And you know it just was one of those things that's been tucked into my memory and when I'm having a bad day or thinking it's not working right, I go back to that and think, no-no, no this is what we need to be doing.

[END OF INTERVIEW]