E: The centennial celebration of AOTA, so we're just.

Lucy: Are you thinking of making some kind of publication or booklet or something?

E: I think there is going to being something of that sorts. I'm sure you'll definitely be notified.

Lucy: Well actually I wasn't on the list. I saw something on Facebook. Well actually I didn't even see. My husband saw it on somebody's Facebook.

E: Oh really? (laughing) Yeah you were nominated actually.

Lucy: Do you know who nominated me or is that private?

E: Yes, let me check. I think I can tell you. Let me see if I can pull that up really quickly. I'm sorry.

Lucy: It's weird. It was such a weird thing because I got, which was lovely, but I didn't know I had it.

E: Well you're very accomplished. Somebody by the name of Patty Laveser I think?

Lucy: Oh wow. Amazing. I don't even know her that well. She is here in Colorado.

E: Yes. Dr. Fleming-Castaldy has heard of you from the grapevine and she thought that, originally, I was doing a project on sensory integration and I was looking into interviewing somebody and she suggested your name, so this is great that this kind of worked out to kind of interview you about your accomplishments and all of that sorts.

Lucy: Ok.

E: So my first question what fueled your passion in researching and analyzing sensory processing disorder?

Lucy: Well it started for me at age 16 when I lost my eye sight and uhm I had a 6 year process of getting more and more less and less vision. I don't know the way to put it, more and more visually impaired. And then my parents brought me to this physician and told them that there was nothing wrong with my eyes. It was in my head. So i was diagnosed with something that didn't exist, which parallels. I mean it didn't exist, like they told me it wasn't a real disorder.

E: Oh wow.

Lucy: Later on, when I was older, when I was in college, it was actually diagnoses with what it was. Which was an eye disease, but at the time I was a teenager, everybody thought I was making it up. So that started and when I had actually the first transplant

that was done in the country, corneal transplant. During that time, 6 months, both of my eyes were patched because you can't move each one at that time. It was very primitive at that time. It wasn't as advanced like it is now. And uhm, so if one eye moves and the other eye moves too, so they catch both eyes and during that period, my touch changed, my hearing changed, you know all my other senses changed.

And I didn't have vision. So I really got interested in sensory and I was headed for law school, but everybody in the hospital, the doctors, the nurses, the nursing students, the residents felt, everyone kept saying "come over and look at this eye, look at this eye." You know, no one even knew that there was a person in there. That was me. So there was one young person who turned out to be an OT student, actually. And I was her project. So uhm, she changed my life by giving me a plate, a plate guard, so I wouldn't get food on myself. And helping me with personal hygiene and things like that. So I decided I wanted to be just like her. I don't even know her name. So I decided to be just like her. We pulled out my idea, my idea of the law school track and started applying to OT schools and I got accepted into BU and I started 2 days after I got the stitches out of my eyes. SO it was the first place I went and when I walked into the doors in Sargeant College right in front of me was this huge poster, sensory integration and learning disorders just released, Ayres book just came out. And I saw there was sensory and I fell in love with the topic and I called Dr. Ayres to see if I could study with her and ended up studying with her that next summer between my first and second year of OT school. She mentored me for 3 months. So that's that story (laughing). Pretty profound.

E: Yeah. That is definitely profound. (laughing). So I'm going to skip around a little bit. So now that you talked about Jean Ayres and kind of you mentoring her, what is your biggest lesson that you feel that you learned from her during your time or just in general?

Lucy: So I would shadow her and from 8 to 12 every Thursday morning, she lectured me, just me, by myself. So we're sitting in two folding chairs, knees almost touching and she is lecturing me on the cerebellum, you know all these stuff in writing since there is no computers. So I was trying to keep up with her. And at 10 until 9, the first day she stopped and she says, "Ok young lady, it's your turn to ask me a question." And I mean I was overwhelmed and awed by her course. And I said, I don't know if I can ask you a question. And she said, "you can't ask me a question, you won't be able to ask yourself a question. If you can't ask yourself a question, you'll never be a researcher." So she folds her arms and she said, "we'll just wait." And we just waited until I came up with a question and I learned early on to ask a lot of questions and never be sure of yourself.

E: Wow. Very interesting. Uhm, so I've read you're the founder of the first sensory processing disorder research program in the Star Institute, how did this institute come to be?

Lucy: Well the foundation actually started in 1979 and it was called the SPD Foundation.

E: Ok

Lucy: Sensory Processing Disorder Foundation. Star is the clinic and that didn't start until 2005.

E: Oh I'm sorry.

Lucy: No I mean it's confusing. It's a little confusing. And then finally, a couple of years ago we did all the paperwork to join the two foundations and now it's the Star Institute for SPD because we put them together. They were both always non-profit, but they had different, one was treatment and one was research and education, and so we put them together. But the research started when, it really took off when the Wallace Foundation found me in 1995. I was Wallace Foundation has a mission to try to find people who are helping and fund them for 3 years.

And they were so excited by my findings that they thought then who should we find next and who should we send next, and so on and so it came out, to make a long story short it came out that I went out of the country to find neuroscientists who were studying sensation, asked them to join our research group, which is the SPD scientific work group and BDFWG and Wallace paid them. So Wallace funded it. I found them, he funded it, and we made a scientific work group, which has now been in existence for 20 years. And Wallace is, this is last year's funding, 2017, so we are having a big celebration conference in Denver in October 6 and 7 to celebrate all the accomplishments of all 50 scientists that have been funded by him.

E: Wow.

Lucy: There is another good story (laughing).

E: You're just full of good stories.

Lucy: My life is a continuous story. All people's lives are.

E: I like that. Uhm so I also read that you have had numerous grant awarded in your name for research and a lot of funding given to you, so what have you found your greatest challenge to be in the research that you conducted on sensory processing disorder or any type of research?

Lucy: Well the greatest challenge is that nobody believed that it was a real disorder. It is not in the DSM yet. Although I spent 18 years trying to get it in the DSM as a separate disorder. So the only way you can get funded is by saying what you want studied. And once they are will to play that game, I wasn't willing to give up on SPD and go over to autism. There are thousands of people studying autism and not very many people studying SPD. So I wanted to know about SPD and I wasn't willing to play that game, because I wasn't, I never got an R01. You have to have an R01 to do serious research in this country. And I funded R01, that was the biggest challenge for me.

E: Wow. Uhm so that brings me to another one of my questions, uhm, so I read that you have also been advocating for sensory processing disorder to appear in two diagnostic manuals, so what was the most difficult aspect of advocating for these SPD to be included in these diagnostic manuals?

Lucy: Well an individual trying to do this, trying to lead the charge, to be an organization. And I am not an organization, I'm just a person. I'm a clinician. I'm a researcher, but I'm not an advocacy person. It's not my strength. We need somebody to do that, who can rally all the chairs, rally all the OTs, and do it for the cause.

I mean I believed in it and I did the best I could do and I did it for 18 years. So that's good, but all kids with autism have SPD, but most kids with SPD don't have autism, they have SPD. So that was the biggest challenge for me because I'm not a gifted, I'm not gifted in that. It's not my strength.

E: So you kind of rallied the troops together and got a bunch of people.

Lucy: I tried to. It obviously wasn't enough. I thought, silly me, I thought that science was the way to prove that it existed. To prove that treatment worked, but it wasn't about science. It was about who you know. And I don't know people. I know OTs, OTs are the least powerful people in the medical hierarchy. So because we have no power, we weren't able, I wasn't able to pull it off. I mean it sounds so stupid to even speak about my personal try, but a single person would try to put that together without the orgainziational support. I mean there is a lot of controversy in OT about sensory integration and sensory processing and it comes from inside and it comes from outside, so you know, it was a battle.

E: So next question, I've read about a bunch of your assessments that you've created, such as the MFUN, the goal, which is assessment that you created do you feel has had the greatest impact on the profession of OT and kind of its use in practice?

Lucy: I think the greatest impact would come from the SP3D Scale. It means standardized (WPS), we are looking for OTs to help us standardize it, so that would be great in this article. I can even give you a link where they can find the type of children that they have access to, it's on our website. It is going to be a sensory processing scale that will help people diagnose and differentiate subtypes of SPD and it has a functional scale as part of it. It has a parent inventory also as part of it. So I think it's going to profoundly change to practice sensation, not just an OT, but for research, there is no criteria right now, where you can say I'm studying SPD kids and here is how we selected because there is no test. The screenings, like the Sensory Profile, but there is no diagnostic assessment so I think that could be the most profound impact I'd like to say I would leave.

E: Very interesting. Very cool. So I just want to bring this back to another question that I have. So I've read that you won the 2004 Award of Merit from the AOTA, besides this award, thus far in your career what do you feel has been the greatest accomplishment?

Lucy: As an award type of thing?

E: Just in general.

Lucy: So the most meaningful to me award that I received was the Martin Luther King Jr. Humanitarian Award. I actually got from the state of Colorado. For 3 decades of trying to help disenfranchised children. And I was so touched by that because you think Martin Luther King, you think race. But you know, the award that gave to me for working with disenfranchised children exactly describes the kids that we see that have no diagnosis, no formal diagnosis that people don't believe and who are desperate that people think they are making things up. You know, it was really meaningful to me in that way. There were also a lot of personal honors (inaudble) with clients that have been extremely meaningful, but as an award, the Martin Luther King Award was really important.

E: What about the clients? I'm sure some of the stories have been very touching and profound?

Lucy: We saw a little boy here at STAR, who was born in New Orleans during Katrina. And he is a triplet and during that time they sent a helicopter to the hospital, which lost all power, in the ICU. One of the triplets died, one of the triplets went with dad to one hospital, and one of the triplets went with mom to another hospital. And we're seeing this child, he is about 10 now. And he's blind, but he has all kinds of sensory problems that we were trying to help him with. He is a brilliant kid, but he crept 1530 (inaudible) and every night he was here, everybody.

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E: It sounds like an incredible experience. I'm getting the chills hearing about it. So you mentioned the controversy with SI before, how do you feel that going forward in future practice for a lesson for future practitioners? How should we go about the use of SI in OT practice?

Lucy: Well, in my humble opinion. The last person in the world to want the treatment to be put into a box is and Ayre's SI makes no sense to me.It makes no sense because she was the one that wanted to grow and in our models, sensory integration is a part

of it that sensory is not the whole story, it is only a part of it. I think OTs have been, they either hate it or love it. That those that love it have been taught to embrace it throughout because to relationships and engagement without regard to arousal regulation. Without regard to context and environment. And I think the problem is that SI is brilliant, Ayre's was brilliant, she had major contributions. I mean she was my first mentor, major contributions to my life and to my theory. But I thought it is not the whole story. And I think it proves, I don't care what words you use by the way, I don't care if you use the word integration word processing. It means the same thing. But the moral of treatment that we use is based on relationships, not based on my relationship with the child, it's based on parents' relationships with the child. So we think of our kids as, we have three clients, one client is the child, one client is the parent, and the third client is the relationship between the child and the parent. That is the client, that we try to see and try to impact and we do it by bringing in the parents into every session. One out of every fifth session is when there are parents only, no kids. So we can make sure they understand to have a lasting effect, you have to have not 5 minutes at the very end of the session, when the parents are in the waiting room or sitting outside of the therapy gym. The parents engage in an active way in the therapy session. So I think that's what has to happen. And I don't really care what really works. We call it sensory processing, we call it the STAR model, we might change it and call it the process model, I'm not sure yet. It doesn't matter what the label is, it matters what the goal is and that you expect your own limitations, being able to meet those goals without the parents being a collaborator.

E: So you mentioned that, obviously you worked with Ayres and then you also mentioned that you worked with a bunch of other mentors, who has had the greatest impact on your life and your career?

Lucy: Ayres, definitely, without a doubt because she launched me into the whole world of sensory. And when I went to study with her, she didn't want to take me. I called her up from BU, Boston, and she said "young lady." I said, "Dr. Ayres, you never heard from me, my name is Lucy Miller and I want to come and shadow you for a summer." And she says, "young lady, I hardly think you are going to spend the rest of your life studying sensory" which I told I was. So I had to meet with her. I had to shadow her. She said, "I hardly think you'll spend the rest of your life studying sensory integration, but anyway we don't have a student program." I said, "I don't need a program, I just need to meet with you and see what you do and how you do it." And she says "I'll talk to my board." And I said, "ok". So now I know "I'll talk to my board" means no because now I have a board. And when I say to them, it means no. But that's the time I didn't know that. So I called her back weeks later and I said "well can I come?" and she said, "no, we just don't have enough resources, we don't have enough people. And we can't meet your needs. So i said ok. So I waited about a month and I called her up and told her "Dr. Ayres, this is Lucy Miller again and I'm sorry to bother you, but I find an educational grant that will pay $100 a week if I can come study with you. And pay you $100 a week if I can come shadow you. She says, "oh $1200, that would be so useful for my new tests, let me see. I'll talk to my board." And she really did talk to her board and I ended up coming, but the trouble was I didn't have a grant,

I just made that up. So now here I am, I have this opportunity to go study with Ayres, but I don't have the $1200. So I called my parents and I explained the whole thing to them and they lend me money and that's how that whole thing happened. (laughing).

E: Wow.

Lucy: I know crazy, huh?

E: Yeah. So what is a big lesson you would like to pass on to the next generation of practitioners in the following upcoming centennial?

Lucy: I think the most important thing is to constantly question yourself. People get into teaching. There are so many people running around the country teaching what they think they know, but they don't know. There are so many things that come up that have no empirical evidence. No base. You have to ask yourself, do I really know this work before you try something. Try it. Try to get some evidence yourself and I'm trying to round up a whole group of people to do, what started ADA, you probably know that ADA. You've heard of that. Ok, so what got them going was 80 stories, case studies, that were published all together, one book. So what I am trying to do is get people together to provide multiple baselines studies, which is the next step up from case studies. A really valid way of doing research. It only takes 3 subjects, perfect for OT, to prove to people multiple baselines, so they can continue up to 50 or 100, we don't know how many we will get. So we can launch evidence based on pediatric OT. We have almost nothing. I mean I've done a lot. We are not ready. We need to get the baseline for empirical research, for evidence-based research has to be set first. And I think people are trying to keep up with the Joneses, the doctors. They are trying, trying to make AOTA, AOTA is trying to do randomized trials because that is the gold standard research, but the field is not ready. So my humble opinion, I think they are on the wrong track. I think we need to train people in an evidence-based research approach that they can absolutely contribute to. So that's my goal from now until I'm done. I'm going to devote all my resources and energy to doing evidence-based research and do it through multiple baselines and other small designs that can be replicated and hopefully leave a legacy of evidence for pediatric OT treatment.

E: So how would you give advice to get into this research field? For future practitioners and myself and my peers?

Lucy: For you, I would say come to our research mentorship, which is in May. Learn how to do a multiple baseline study and what we do is we teaching in the morning, design the studies in the afternoon, get the study designed. It is a reasonable study, you can do it with 3 kids at different times, perfect for anybody working with kids. And start small and learn yourself. Don't just wish. Don't just wish. You've got to start somewhere. Start small, be successful. It's the same as working with the kids. Where do we want our kids to go. Start small and meet them where they are at. We work on success. Same with research. It's the same thing. You can't start big. You can't start with a randomized trial or you'll never get where you are going.

E: Baby steps, building blocks. That makes a lot of sense, especially in all of these educational curriculums, evidence based research is being nailed into us, but it's kind of like how do we get into that.

Lucy: Exactly. And how can they expect you to contribute. They don't tell you how. They just say you have to. It is so important that they get that. Now I know this and that, but what can I do? Nobody is talking to you about what you can do. So they're just telling you that you have to do it. That does no good. It's like saying to a child with CP, you have to walk. You have to stop drooling. No, we would never do that with a child. It's a developmental process. You can learn to do research, but you can't learn by reading papers and analyzing what's wrong with the research that people have done. You start by doing you're own small study, one foot forward at a time. Then we as a profession, needs to have resources for people like you, like all of you, who need to start small and do one good study and get it published and another good study. There is not even any training available. I think the profession has an obligation to its younger members to train them, not just to tell them we need evidence- based practice. Everybody understands that now in the field. But nobody is trying to help you do you're own small projects so you can get your foot in the door. That's something I think AOTA has to go, not to be universities. People who already know research, they don't need funding, you need it, all of you.

E: The little guys who are wanting to get involved.

Lucy: Exactly. And there are ways for you to get involved. You can get involved. Having a good project, that's how you get mentored. But you don't even know the process for that, which is a whole other story.

E: Alright. Do you still have time?

Lucy: Do you have another question?

E: I don't have another specific question, but if you have any last words, last remarks, summing everything up that you want to?

Lucy: I just want to thank people that nominated me and tell them what a great honor it is. Very surprising, unexpected, and wonderful because on a day like this in Colorado, you get kind of desperate, you know, working alone and well I'm not alone, I have a big organization and I have a lot of OTs, but they're on a day to day level. So it's a big gratitude and it means a lot. So I just wanted to thank you for your call and your time and for being part of the celebration.

E: I thank you.

Lucy: Are they going to celebrate in Philadelphia?

E: I think, I'm not 100% sure, but I know that it's going to be a little bit bigger than the past ones, but I can definitely keep in contact and let you know

Lucy: Well if you hear anything, let me know because I'll probably be the last to know. And I want to make sure I have it on my schedule.

E: I will definitely let you know and I will be there and Dr. Fleming-Castaldy will be there. We'll try to hunt you down. I know I talked to Dr. Schoen and she told me that you guys were going to be there.

Lucy: Well we have a preconference institute and an invited institute by AOTA. It will be on occupation of course. It's really on the SPD-III, the new test. So you can find us ahead of time at the preconference. It's not even a lot of hotel reservations left.

E: I know. We got ours very far in advanced. So we're lucky.

Lucy: We didn't know about it. So we missed out on that, but that's alright. I don't usually come but this year we are speaking. Thank you for your time. I really appreciate it.

E: Thank you for your time. I just have to send you release forms.

Lucy: Yeah. Send it to lucy.miller@spdstar.org.

E: Thank you so much. I really appreciate it.

Lucy: You're welcome. Have a good time.

E: You too. Bye.