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• *A New Therapeutic Paradigm* •

• **From “Doing” to “Being”** •

• Revolutionary Common Sense from Kathie Snow, www.disabilityisnatural.com •

I wrote Disability is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities for parents and others who care about/for children with disabilities. I hoped it might also help professionals in the field, but I didn't know if any would value the words of a parent. Imagine my surprise (and delight) when several universities placed quantity orders for my book! At the University of Oklahoma Health Sciences Center (OUHSC), my book is the primary text for an entry level Master's OT/PT class. I felt an interview with these extraordinary teachers could provide exciting and valuable information to others.

You'll hear from Beth DeGrace (Occupational Therapist, Ph.D., and Assistant Professor), Rene Daman (Physical Therapist, M.S., and Adjunct Professor), and Lorrie Sylvester (Physical Therapist, M.S., and Adjunct Professor). They have many years of experience in a wide variety of arenas: institutions, hospitals, therapy clinics, private and public schools, and NICUs; they've provided Early Intervention services, consultations to state agencies, and employment assistance; and they now focus on “doing things differently” to ensure people with disabilities and their families live their dreams in inclusive environments. Their evolutionary experiences and hopes for the future are enlightening.

Q: *The class you're teaching is very different from other classes for PTs and OTs. Before we get into that, however, can you describe the initial training and education you received as students?*

BETH: As an OT, I was trained in the traditional way: to look at diagnoses. For example, if a child has cerebral palsy (CP), you do “these” assessments and provide “this type” of therapy.

LORRIE: Same here! I remember being asked by an MD to do heel cord stretches on a young man who was labeled a “toe walker.” Given that the man had been toe-walking for many years, his ankles were “stuck.” I told the MD that major surgery was the only way this guy would stop walking on his toes, and that neither stretching or casting would make a change. (He was not a candidate for surgery at his age.) This man still walks today—up on his toes. The things we were taught in school related to typical development and integrating reflexes—like trying to prevent certain reflexes and their reactions. But these clearly don't work with older kids and adults.

Q: *Sounds like you're talking about NDT (neurodevelopmental therapy), which was all the rage when my son was very young. His therapists said NDT focused on trying to get a child to achieve typical development through specific techniques. But I thought NDT was just for young children.*

LORRIE: No, we were taught it was appropriate for *anyone* with neurological issues. But I found it doesn't work with older kids and young adults with developmental disabilities, and it isn't necessarily better for babies and children. Many of the techniques may be useful to help new parents feel more comfortable in holding and positioning their

babies/children. But the “developmental approach,” at the expense of other learning, is not useful. If someone is never going to achieve “developmental milestones” then we should help her move on with her life.

BETH: You can tell when things begin to shift by what's discussed at conferences. Eight years ago at our big annual therapists' conference, presentations on NDT were in the majority. At the last conference, there were only a few NDT workshops. But once a therapist is in a clinical practice, it's easy to hang your hat on whatever you learned in college and not go any further.

RENE: There are new theories on how people learn to move or accomplish a task, and some therapists *are* modifying how they practice. But I'm amazed that many of the therapists I meet don't know about these newer theories, such as motor learning and motor control. It's as if some therapists stop learning once they're out of school.

BETH: I think many universities *are* changing the way they teach today, but there is often a very big discrepancy between what PT and OT students are taught and what's actually happening in therapy settings. We still see kids crying during therapy, parents being told to sit in the waiting room, therapy in meaningless environments, and other ineffective practices.

LORRIE: And this can be very difficult for the student. When you're a student, you aren't always comfortable challenging the old style of therapy that's practiced in the clinics and settings you visit, especially when your grade depends on passing this experience.

Q: *How is the class you're teaching (“Neurological Issues and Interventions”) different from the way you were taught?*

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BETH: We begin by talking about children without disabilities and the importance of every child having opportunities to participate in typical environments and activities. We also talk about ways of looking at children differently—as children, first—instead of diagnoses, and the importance of focusing on children’s interests and abilities, what they want to do, need to do, and are expected to do. Then problem-solving the supports they need to do these things emerges. Students soon realize that the only way to learn these things is by *talking* to the child and the family! And when this occurs, we see very positive outcomes for the child and family. We want our students to first learn what’s important to the child. We don’t get into typical therapeutic issues—like assessments—until two months into the class.

RENE: And beyond focusing on what the child wants to do, we help students learn about the cultural piece. For example, what is the environment in a school classroom? What are expectations for the child? How can I influence the teacher’s expectations of the child in that environment? Sometimes you can best support the child by addressing what’s going on in the environment. Developing peer supports, providing information to the teacher, or developing architectural supports are the things that may really make a difference.

BETH: Our students do a great deal of work in environments where typical children are so they can learn about the cultural environment and what it takes for all kids to be successful—in the area of friendships, dealing with peers, opportunities for participation, and more. Our students can’t help children with disabilities be successful in these environments if they’re not familiar with them.

LORRIE: The class also helps students learn about assistive technology (AT)—something most therapists, including us, were not taught. They learn about high-tech and low-tech devices that can enable a child to do what she wants: have mobility, communication, or whatever!

Many therapists haven’t seen AT as part of their responsibility—it’s been left in the hands of durable medical equipment dealers or physicians—but we think expertise in AT is a very important part of a therapist’s role. Our class may be unique in focusing on this issue. We have another class that focuses solely on AT, in which students complete a project of finding an AT solution to meet a child’s needs, so the child can do what he wants to do.

Q: Let’s go back for a moment. You were all taught differently than the way you’re teaching today’s students. What caused you to change?

BETH: I kept going back to school—and ended up with three degrees—because I felt like I must have missed something! As an OT, I was trained to believe that my job was to help people occupy their time doing what they wanted to do, and that when this happens, a person is in good shape. But in practice—in a therapy clinic—it made me sick to pull kids away from their parents, put them on scooter boards, and charge money for this!

I wondered, “How is what I’m doing having a positive impact on kids’ lives? Maybe I’m not doing the right stuff, maybe I didn’t learn it right, maybe I missed something.” I went back for my Ph.D. so I could do research on how to do things better.

I worked in a school for kids with autism and I interviewed the families. I learned that their worlds revolved around the condition of autism. They had very difficult days and nights, and they couldn’t enjoy vacations or even family dinners! I thought, “Shame on me!” I had been doing things *to* kids, but had done nothing to help the family as a whole! Putting a kid on a scooter board is not going to “fix” him. I realized I needed to focus on doing things so a child and his family could have good days and nights, good family vacations, good dinners, or anything else!

RENE: My experience is somewhat similar. I came back for my Master’s, and am now working on my Ph.D., so I could learn more and do better. Before coming back for my Master’s, I worked in a therapy clinic with therapists who had more experience. I felt they were the experts—they were NDT certified and it seemed what they were doing must be the “right” thing to do. But as I mentioned before, I was uncomfortable with many therapeutic practices and I wanted to learn much more.

As a PT, your goal is to help a child learn to access the environment. But over and over again, when I suggested that parents might want to consider getting a wheelchair for a child so he could have independent mobility, parents would say, “But if we get him a wheelchair, he’ll never learn to walk.” I needed to understand all this better: the resistance, fear, grief, guilt, or whatever. So for my Master’s thesis, I interviewed nine families whose children used wheelchairs to better understand the process parents go through in accepting their child’s disability as it relates to equipment and supports. This was the first time I had really *listened and talked* to families—letting them take the lead and tell me their stories. We were taught to “interview” families to gather treatment-focused information. But this really helped me learn to value the family and acquire new ways of thinking.

Next, parents need to realize that there is no evidence to support the notion that therapy “fixes” people with developmental disabilities.

LORRIE: My change came from having a friend with cerebral palsy who had lived in an institution for many years. She finally got out and moved into her own apartment. I went to visit her one day and we talked about how things were going—with cooking, laundry, and so forth. Things were going fine, but she told me she was still having to go to PT and OT in town. When I asked why, she said the therapists were worried about her range of motion. Well, she had better range of motion than I did! Yet the therapists weren't helping her learn to do what she needed to do in her new home. She wasn't getting support for the things that were really important to her.

BETH: The class we're teaching challenges the developmental model. We look at outcomes in terms of participation: “Is the person able to do what he wants to do? Can he participate in the activities he enjoys and those he is expected to do?”

Doing therapy to change a child doesn't work!

For example, an outcome shouldn't be that a child will crawl, but that he can participate in what he wants to do! It shouldn't be that a child can hold a spoon, but that she can spend mealtimes with her family. When a therapist can help a child and her family spend time doing what's important to them, developmental milestones are practically irrelevant.

We decided to use your book because it put words and stories and examples to ideas I had been thinking about for years, relative to a therapist's goal of supporting and assisting families to be successful. It's an awesome tool and a powerful agent of change.

RENE: Some of us were already moving in that new direction—looking at people as people, first. And a parent's words and experiences—like your book—are more powerful than anything we (as teachers) can ever say. We wanted our students to think differently and your book helps them do that. It teaches them to look at children in terms of strengths and competencies, and the importance of being a part of everyday situations.

LORRIE: Your book also helps our students understand that having a developmental disability is a natural part of life. Our students are learning that a child with a label is a child, first—he's not sick. And our job is to help discover the supports he'll need to be successful and happy in life.

BETH: Many therapists are taught to focus on “components of performance.” We're asking students to go beyond that—to move from providing treatment to listening and supporting. Recently, Lorrie and I presented at our state's OT conference on the new ways we are doing things. A therapist came up to me afterwards and said, “You're asking me to change my identity!” All therapists have the ability to help people live the lives they want, but many may need to shift their thinking.

Q: From your perspectives—as therapists— why do we need to do things differently?

LORRIE: *Doing therapy to change a child doesn't work!* I do some work in employment now—helping adults with disabilities be successful in real jobs, included in their communities. The kids I treated years ago have now grown up, and some are coming back to me. They still have CP or whatever! Therapy didn't make the condition go away. As kids, they all had dreams—none of which were addressed during typical therapies—and now they want to work. It makes me want to cry that I didn't listen to their dreams

when they were children. If I had spent more time listening to their dreams and helping them do what was important to them, maybe they would have gone on to college or done other things to be

successful as adults. I'm doing my best to help them be successful now, but things could have been so different!

RENE: I agree. The most important thing we can do, as therapists, is to help a child have the best quality of life, *as defined by the child and the family!* And we have to question whether making a child go to therapy two or three times a week really contributes to a child's quality of life, like you write about in your book. When kids are going to therapy all the time, they're missing out on ballet or karate, playing, and so many other typical opportunities. It's so sad that we've believed therapy was more valuable than listening to what a child thought was important.

LORRIE: When I was a child, I had three knee surgeries, and was taken to PT all the time. My mom had to drag all four kids to therapy or else find a babysitter. It was hard on the whole family. I missed out on doing lots of things that were important to me. And I remember, just as clearly as if it happened yesterday, that I was always scared to death of being taken away from my mom by the therapist—even when I was a ten-year-old! And much of the therapy really hurt—I remember that very clearly, too. I cried a lot, and the therapist just ignored my tears and pain. Well, my dad was a bricklayer—he was very handy and very creative. He figured out how to help me do the exercises at home so I wouldn't have to go to therapy. I have a lot of empathy for what many children go through with traditional therapies.

RENE: I never felt right about trying to treat a child when he's crying. And once I read an article by an adult who received lots of therapy, and he wrote about feeling violated by the therapist's hands.

LORRIE: One of our colleagues related an incident that happened when she was working at a hospital therapy clinic. A 60-something woman was receiving therapy

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after having a stroke. The male therapist was using NDT methods—trying to get her to replicate typical developmental movements. Well, he had this woman on her hands and knees. He squatted behind her and would tap her “gluteals” (her behind) to initiate movement. This dignified older woman was crying—she felt so demeaned. And the therapist simply continued! Our colleague tried to intervene, was unsuccessful, and was then chewed out by the supervising therapist! This is the kind of stuff that routinely occurs when we use the deficit-based approach. *You no longer think about the person as a human being, you only think about function and technique.*

RENE: I remember treating a 14-year-old boy on a mat to stretch his hamstrings. I realized how boring it was for me, and I assumed it was even more boring for him (and probably painful). I thought, “What am I accomplishing? This doesn’t help him do what he wants to do!” I realized there were other ways to help him do what was important to him, instead of doing what was important per the “therapy plan.”

LORRIE: Yes, we need to ask, “What is this accomplishing?” A lot of what we do could be done better in different locations—like the YMCA or a gym—places in the real world. It’s lots more fun and more meaningful to the person.

Q: What’s the “new role” for therapists?

BETH: We’re helping students think in terms of being more like a “coach”—working with individuals, with families, and with communities—instead of simply providing hands-on therapies to a body.

RENE: Therapists need to be open-minded and look at the bigger picture. We’re teaching our students that their role is to support children and families so they can do what they want to do. If a family tells us eating out is important, and the child needs behavior supports, we need to figure out what will enable the child and his family to have a successful experience dining out. Ditto if the child wants to play T-ball or do anything else!

LORRIE: I got a call the other day regarding a man who uses a wheelchair and his swimming experience. The human services staff person who called indicated it would take “triple staffing” (three people) for this man to go swimming. I couldn’t understand how the staffer had come to this conclusion. I asked if the pool had a pool lift. It did. Now I *really* couldn’t see where the problem was. Actually, no one had thought about this very much, and no one talked to the man who uses the wheelchair. I met them all

at the pool, the lifeguard showed me how the lift worked, and then I showed everyone how the swimmer could easily be transferred using the lift, with help from one person and a little assistance from the lifeguard. No one had ever thought of asking for help from the lifeguard or pool staff. Being a coach and helping find natural solutions is a very important role therapists can and should assume. Asking for help is normal.

RENE: Another role is to help families tap into the natural supports in their communities—by providing them with information on what’s available and brainstorming ways to make it happen so they can lead typical lives. And as we’ve said, we need to focus on what’s really important to a person and his family.

Sadly, therapists can often have a very negative influence on parents, by sending the message that a therapeutic activity—like stacking donut rings—is so important! Again, we need to focus on what’s really important in someone’s daily life.

And we have to question whether making a child go to therapy two or three times a week really contributes to a child’s quality of life, like you write about in your book.

Q: What about therapy and early intervention for very young children?

RENE: The state of Oklahoma has a pretty good model: services are provided in natural environments. Therapists go to the child’s home, the childcare center, the grocery store, or wherever the child is. Therapists are taught to use the coaching model, in order to help the family, the teachers, or anyone else in the child’s life become the “expert” in the best strategies and techniques to assist or support a child.

LORRIE: We also believe therapists can and should help others learn about seating and positioning, assistive technology, and how to adapt things. It’s critical to look at the rhythm of a person’s day. I remember one family I visited: they had an antique “duck” rocking chair that had been in the family for generations. The mother told me the history of this duck chair, and she hoped her child with a disability could enjoy it just like others in the family. So I made a seating insert to enable the child to sit in the duck chair. Our efforts shouldn’t be limited to traditional therapeutic activities! We can help families learn to make or adapt things around the house and more. Some families have great ideas and know how to do these things; others don’t and we can help!

BETH: It’s about looking at the “power of the ordinary.” What are the typical activities one wants to do? And what does it take to do that? We need to consider the “cost” of therapy, not just the financial cost, but the cost in terms of robbing people of the opportunities to enjoy ordinary activities. If a child is being taken to therapy all the time, is

there time and energy left to take him to the park to play? What is a person missing if he’s always going to therapy? There is such great power in the ordinary.

Q: What about the way therapies are typically provided (pull-out) in public schools?

RENE: We need to stop the pull-out. We need to become a support to the classroom, to ensure a child’s successful participation in the general ed classroom, whether that’s during academics, PE, art, music, or whatever. To do this, we must *be* in the same location as the child, and pull-out can’t achieve this. If we do our job right, we build relationships with educators and administrators so *all* kids have opportunities. You can’t do this by pulling a kid out.

LORRIE: Our focus should be on what’s really going to make a difference in that child’s school day. A kid might need help learning to get on and off the bus. If so, I must be where the bus is at the right time. And as soon as the child can do it for himself, I’m no longer needed!

BETH: We’re also helping our students widen the focus from the individual to the environment. They learn to consider what needs to change in the environment to ensure a child will develop friendships, have successful learning opportunities, and more.

LORRIE: The more you’re in the classroom, you become a better helper. Lots of people come into classrooms to help: parents, grandparents, and other volunteers. When you’re in the classroom instead of pulling kids out you become just another helper and that’s a great thing! I knew this was all working when a couple of kids came up to me and said, “We know whose grandma *you* are!” Well, I’m actually not anyone’s grandma! But it was great that the kids saw me that way—they didn’t know I was a physical therapist! When you’re in the classroom, you’re there for the whole classroom, including the teacher.

One challenge was helping a teacher learn new ways of thinking. When she saw me come in the classroom, she automatically said, “You can take him out,” because she was accustomed to pull-out. I told her I just wanted to hang out. We’re helping our students learn how to “hang out with intent”—and my intent was to see what needed to happen in this classroom so the child and his teacher were successful. I had been told that the child needed this-and-that. But the longer I hung out, the teacher became more comfortable with me and began telling me about other things that could help this student be more successful. This never happens with pull-out!

RENE: When I first started doing stuff in the classroom, I had a bit of an identity crisis when I realized that *anyone* could do what I was doing!

Q: That’s what happened to one of the school therapists who worked with my son. When we wanted her to help Benjamin with keyboarding skills, she got huffy and said, “That’s not therapy! Anyone can do that!” I think she was having an identity crisis. So how did you resolve this issue?

RENE: By realizing that what I was doing in the classroom was *far more important to a student’s success* than anything I could do in pull-out! In many instances, therapists *do* have unique knowledge about assistive technology, modifications, or other strategies to create positive change. In other cases, *others* might be able to do what we do just as well. As a therapist, you *do* need to recognize when you don’t need to be there. We need to know when to get out of the way!

Q: What about working within community activities (T-ball, karate, dance, etc.)?

LORRIE: That can be very important. First, therapists can be instrumental in helping families learn what’s available in their communities, as Rene mentioned earlier. Second, we can work with families and the staffs of community activities on ways to ensure people with disabilities/families can use or enjoy those activities in the same ways other people do.

Q: How can parents best help their children, in relation to therapy?

LORRIE: By talking to their kids about their hopes and dreams, and doing whatever it takes so a child does *not* go to therapy! Parents need to help their kids pursue their dreams, and going to therapy can clutter those dreams. Therapy, goals, and all that stuff makes us lose sight of dreams. We’re reduced to thinking about some therapy goal instead of what’s really important.

BETH: Parents also need to focus on a child’s strengths and interests. If families share this information with therapists—along with their hopes and dreams—that would help therapists be “opportunity focused” instead of “technique focused.” This would also enable us to be more effective helpers, and meet the real needs of people.

LORRIE: I hope parents and people with disabilities can learn to use therapists on an “as needed” basis. There shouldn’t be this lifelong relationship of “provider/recipient.” That creates intimidation and dependence—not a good relationship.

RENE: People with disabilities and families need to feel they can call us anytime they need us, and they don’t need us all the time. A therapist should be someone who comes in and out of your life, not someone who is a permanent fixture!

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Q: In general, what should parents expect from therapists?

BETH: First, parents should ask a therapist what her role is. Not, “Are you an NDT therapist,” but what the *real* role is. Is the therapist there to “fix the child” or to help the child and the family live a life of participation, opportunities, and more?

We need to stop the pull-out.

Next, parents need to realize that *there is no evidence to support the notion that therapy “fixes” people with developmental disabilities.* Therapy is not a cure! If it was, there would be no adults with developmental disabilities!

Before a therapist touches a child, parents should ask, “Can you show me the evidence that what you want to do is effective?” And once a therapist has started working on a particular thing, if there isn’t change within a reasonable amount of time, the therapist needs to stop wasting time and money!

RENE: Therapy can, in some cases, *prevent* things from happening. For example, if a child is walking on the sides of the feet, there are things we can do to help this. But that doesn’t mean I need to see the kid two times a week for the rest of his life! Our job is to help kids be the best they can be, not to “cure” or “fix” children.

Things are constantly changing, and therapists cannot simply assume that what they learned in school is the only way to do things. We’re teaching our students how to look critically at evidence-based practices, with the hope that they’ll continue to do this during their careers. Therapists need to discriminate between “evidence” and “promotion.” An article in a magazine or newspaper is not evidence! In addition, when someone comes up with a new therapy or intervention, they do their own studies. This is passed off as “research” when it’s actually the creator promoting the product. Therapists, as well as parents, need to be aware of the difference!

LORRIE: When parents ask questions like, “When is my child going to walk?” Therapists need to be able to say, “I don’t know.” They also need to be familiar with research so they can give an informed opinion, such as, “According to the research studies I’ve read, and based on what I know about your child, walking may not be a possibility.” We need to be as honest as we can, based on what we know at the time. Therapists have a responsibility to

share as much information as possible—journal evidence, research, etc.—with parents. Parents can also research things on their own, via medical school libraries, OT/PT departments at colleges and universities, or checking what’s available on the Internet. And it’s just as important for parents to distinguish between true research and “promotion” of techniques and practices.

Q: Can you describe a desirable view of the future, as it relates to therapeutic services?

BETH: One of the things we’re trying to infuse in our curriculum is a focus on healthy lifestyles, which means doing what *you* want to do that promotes your health, well-being, and quality of life.

Q: What do you mean by “health and well-being?” Because my son uses a wheelchair, some people would say he’s “not healthy.”

BETH: Oh, thanks for asking that question! No, we don’t see health and well-being in the traditional medical sense. Like quality of life, health and well-being are defined by the person! And in this context of promoting a healthy life, a therapist could be thought of as a “life” coach, someone there to help when a person needs assistance in orchestrating her life so she can enjoy typical, everyday activities.

Traditionally, we’ve focused on a hands-on approach to get a person “doing.” But we feel it’s more helpful to use a person’s hopes and dreams and focus on a person “becoming” and “being” What could be more important than that?

My thanks to Beth, Rene, and Lorrie for their willingness to share their time and expertise for this interview. I’m very grateful for their efforts, which will positively impact children with disabilities, their families, and their communities now and for years to come.

Beth shared the following website addresses of interest:

www.puckett.org/poweroftheordinary.php

www.otseeker.com

www.coachinginearlychildhood.org

www.pedro.org.au

www.evidencebasedpractices.org