

The International Journal for Direct Support Professionals

Reflections from the Other Side of Retirement

By: Susan Stewart
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An introduction from the editors:

We wanted to start the year by asking two recently retired women about their career in working with people with Intellectual Disabilities – what they learned from their work, and what gifts they received that they were able to take into retirement, and into the rest of their lives. We thought that, as it is the New Year, we would like to celebrate by, again, exploring the way we grow as people, not just as professionals from the work we do. Welcome to Belinda and Susan.

Susan: I enjoyed a relatively short career of 15 years in developmental services. I was a stay-at-home mom before that, going back to school and entering the workforce in my mid-forties. This has given me the unique opportunity to be able to compare who I was 'before,' and how I changed 'after' my work with people with disabilities. Although I entered the workforce quite late in life, I took my work very seriously and determined to make as much of a difference as I could in the 15 or so years before taking advantage of the opportunity to retire. I remain active in the field, not as a professional, but as a friend and advocate of several people with Intellectual Disabilities. By the time this newsletter is released, I will also be working more formally as a volunteer and helping out with some administrative work in a group home environment.

Though limited in duration, I am beyond grateful for a job I loved, which drew me in because I wanted to be able, at the end of the day, to say, "I made a difference in someone's life." I had no idea the biggest difference that was going to be made was in me. Some of the gifts I took away are indefinable and indescribable – attitudes and outlooks, ways of 'being.' There are some I can only attempt here to express.

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Belinda: I began my apprenticeship in the field of developmental services, as an ‘Approved Home Parent’ in 1974, as a very green 24 year old. The Approved Home was intended to be a stepping stone between the institution and community living for people with Intellectual Disabilities. It was a place to learn skills and move to further independence. My husband, Paul, and I, with our two pre-school children, moved into a farmhouse that eventually housed 12 men from Pine Ridge, a local institution, where Paul also worked as a manager who wanted to make change in the system. Twelve people with disabilities living together would not seem acceptable today, but living together with people with disabilities for what turned out to be nine years, formed my own strong philosophy of support. Simply, I learned that all people have common needs in life, and a mixed bag of human strengths and weaknesses, regardless of intellectual capacity.

As community living in smaller settings became the benchmark, I began what was to be a 32-year career working for an agency called Christian Horizons. My first position was director of the home we had lived in, only now with a staff team. I retired in 2015 as an Area Manager.

Susan’s Gifts

Gift One: Perhaps the greatest gift I took with me into retirement is the richness and depth of the relationships I have with my grandchildren. The relationships I developed at work gave me skills and insights I couldn’t have fathomed before that. Simple skills but effective. In fact, in preparing to write this article, I asked my daughter (who also works in the field), “Can you see a difference in the way I relate to my grandchildren as opposed to how I was with you kids?” She replied emphatically. “Absolutely. You even changed as a parent once you started working and picking up things at work.”

One of the things I gained, was simply how to ‘respect’ others, how to exemplify and model it so that they knew they were respected. I learned that there is great power in that. My grandkids tend to come to me with their problems, I think, because they know that, though I may disagree with them, they will be respected, listened to and valued as whole people. I have learned how important it is to them that I see them as equals; I never talk ‘down’ to them or lecture, or judge and, if I ask enough questions, and share some of my own experience, it turns out that they usually have the answers they need within themselves. I don’t need to lecture them. They know, when they come to me, they will not be disrespected. And in turn, they respect me.

That is an incredible gift to have their respect. Not because I command it but simply because they can’t seem to help but return what is extended to them. When I had my children, I had accepted the mistaken idea that each one was a blank page and I would be able to form them into who I thought they should be. As can be imagined, I learned (they taught me!) that this theory wasn’t going to work out so well – for me, or for them. But I still treated them in ways I regret now. I really didn’t know any better. Fortunately, they are awesome people who turned out amazingly well in spite of their mother’s misguided efforts. But I am grateful to have been given a second chance – the chance to be an influence on a whole new set of younger people. These were lessons that I learned both in the classroom, but more importantly, from the individual people I worked with and supported. Respect begets respect. It’s the right thing to do, and it’s a wonderful thing to be on the receiving end of.

Gift Two: Another gift is to see that each and every person has intrinsic value – that everyone has a contribution to make to the community, and that if anyone is missing from the community, then everyone loses. I remember being afraid of difference. I felt awkward around people with disabilities. I was afraid I would say or do the wrong thing and inadvertently offend. I am shocked at my own ignorance now, but I remember saying very early on that I thought we needed a handbook of some sort because, “I don’t know even the basics – like what do we call ‘them’?” The answer I received was, “People. You call them ‘people’.” It stopped me in my tracks. That simple understanding that we are much more the same than we are different was a foundational building block on my becoming more ‘human,’ as well as a warmer and more welcoming person to others. I am no longer afraid of ‘difference,’ in fact, I celebrate it and welcome it. I make a point of speaking to people with disabilities I run into when I am out and about because I know that, very often, they are treated as invisible, and their difference is feared.

Gift Three: Another and very precious gift was the ability I gained to help my own father and to, finally (in my fifties), feel that I had earned his respect. We had always had a difficult relationship. When compared to my siblings, I always came up short. I had resigned myself to my position on the lowest peg of my family ladder and the least in value in his estimation. This was a source, understandably, of lifelong personal pain – of feeling I could never ‘measure up.’ My father’s disability came as a result of his service in World War II. He was paralyzed for six months in his early twenties and, though he had partially recovered, he never regained full function of the lower half of his body. As he aged, it worsened for him, until in his 80’s, arrangements were made for him to be transferred from a short-term stay in hospital, directly to a nursing home. He called me at work to give me the news that he would never be going home again, and his voice was terribly sad. I asked him if this was what HE wanted to do. He said, “No, he didn’t,” but he had uncharacteristically resigned himself to the inevitable. His doctor, the hospital social worker, and another family member all had agreed that this was the end of his independence and, not knowing of any other possibilities, he was quietly coming to terms with his new reality.

Although I wasn’t working directly with people with physical disabilities, I had picked up enough knowledge from working in the field to know that there were many things that could be done to help people to live at home as long as possible – even those nearing the end of their life and with extensive disabilities. More importantly, I learned that it was not my opinion that counted – or another family member’s, or a social worker, or anyone else’s. It was my dad’s opinion alone that mattered. I asked him if I could advocate for him and try to find out if there might be a solution that would make his preference to go back to his home possible. I was sure that something could be done at least to delay a move to long-term care, if not prevent it altogether. He was reluctant only because he couldn’t see what good it would do, but he did give me permission. I will never forget my joy at his case conference a few days later. The look on his face changed from despair to hope as it became clear to him that the supports he needed to return home could be managed, and quite easily in fact. Because I had learned what person-centered support was all about and to advocate for others, my dad was able to spend his final 18 months at home and never did have to go into long-term care. Had I not worked in developmental services, I would not have had the skills and the knowledge to support him in his decision. For the first time in my life, I felt my father’s respect. I was the only one of my siblings who was able to help him in this area. It was a gift beyond measure.

Belinda's Gifts

Gift 4: A gift I was extremely grateful for was learning to break down a person's need for support into small teaching steps called a task analysis. When my mother was incapacitated by a stroke in 2003, I went to England after her first few months of recovery to help her get out of hospital and get her life back. Her communication was compromised, but I was desperate that she be seen as an individual with abilities, not just disabilities. I did not want her to lose what capacity she had because of someone doing for her the things that she could do for herself. I wanted her to be able to retain her daily routines and express her unique preferences through them. I spent hours 'writing her life' in painstaking detail, so that whoever came to her home to support her, would know 'her.' It gave me great comfort to pave the way for her homecoming by doing this and other things, such as connecting her with a hairdresser who would come to her home and know how she liked her hair done. All of this was easier due to skills that were gifts from my work. I have often reflected on the importance of doing this job well for those who are as vulnerable as my mother was, and the fact that we can all become that vulnerable person as we age. It was hard to see my mother's most private needs be taken care of by a stream of different people coming into her home, and while there were a few helpers who were careless or distracted as they provided support, eventually there was a core group of wonderful staff who knew her and loved her.

Gift 5: Another gift was learning the power of little things and the art of relationship. A Christmas or birthday card for someone who otherwise would get nothing matters. There are never enough resources, and yet the most precious resource is time, just being with someone. My office used to be in the basement of a community residence, and sometimes the door to the basement would suddenly be yanked open, and a person who lived there would stomp down to my office and knock rapidly on the door. Talking loudly, he would pace up and down with reddened face and wide eyes. I would talk about how a cup of tea always made me feel better, and ask if he'd like an herbal tea from the stash on my shelf. Eventually he started coming down to ask for an herbal tea when he felt stressed. I called it 'tea prn,' and it always did the trick. I did ask if he wanted to make himself the tea, but he wasn't interested in that, and I didn't push it because knowing when to teach and when to simply come alongside someone is important. People think that quality care is all about money, but time is the most precious commodity we have—just being with someone. This was reinforced by another experience: 3:00 p.m. was becoming a tense time each day as upstairs, people planned their evening—who was going where and with whom. When negotiations escalated to shouting and stomping, and eventually a window being kicked through one day, I asked the feisty fighters if they'd like to form an anger management group, and they said, 'yes.' I didn't have a lot of time, so we met once a month on Friday afternoons and worked through an excellent anger management curriculum over 12 months. Each person had a binder in which they kept their work, and we not only learned anger management together, but had a lot of fun doing so. We even had a fish that sang, "Don't Worry—Be Happy." I still get asked, "When are we going to do Anger Management again?" when I meet a certain person from the group. He doesn't need an anger management refresher, it was the time we spent together on those Friday afternoons that made a huge difference, and the camaraderie of learning something together is what he is

really missing. Like one of our granddaughters who loved butter so much that we always said the bun was just the vehicle for getting it to her mouth, I think that's often the case with programs. It's the attention given to people while participating in them that is the real gift that makes the difference.

Gift 6: I learned, too, that the work we do is never finished. When I entered the field in 1974, Paul was fighting to make changes within the institution that resulted in more humane care and support in that setting. These changes were as basic as getting permission for bathrobes for people to wear as they waited in line for showers. It's pretty shocking to think that this was not a given—but at that time, it wasn't. Throughout the years, whenever we thought we were getting 'there,' that mythical destination where things are done ethically, professionally and just plain 'right,' I have learned that it isn't we who know when it's 'right,' but the people on the receiving end. "If you want to know if the shoe fits, ask the person who is wearing it." I remember the birth of the People First movement. Their work and their words made us realize our complacency in thinking we were doing good work, yet being the ones deciding what that looked like. Learning that, no matter how much we think we know, we should never think we've arrived, is a great gift to take into retirement. It's the gift of continuous learning and the ability to stay curious and open. This is a critical element of staying relevant in a changing environment. Supports of the past will not necessarily support the needs of people today. As people are integrated into communities of belonging, their support needs will differ.

To Conclude: The job title for Direct Support Professionals when I started in this work was 'Residential Counselor,' and the role was often interpreted in a parental manner—we have come far since then. The current title denotes ethical and safe practice—and that's what I see in many of the staff of today. But remember--the work is never finished—there is always more to learn as the people we support teach us how to do better. And as we entrust the work we loved to a new and fresh-eyed generation, we believe it's in good hands! We hope that you continue to put people before paper, that you take time to listen and talk with people, and that you are brave enough to challenge the system—because you may be one of those who change it from the inside, for the better—and then get ready to receive the many, many gifts that will enrich your own life.

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