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CHAPTER 4

"The stairs didn't go anywhere!": A Self-Advocate's Reflections on Specialized Services and their Impact on People with Disabilities

Michael F. Giangreco

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Michael: Norman, thanks for taking time to sit down with me. Let's start by establishing what specialized services you received when you were in school.

Norman: Physiotherapy, occupational therapy, and speech therapy. Each specialist had her own room and they would pull me out of my c

or that all of us must be lonely or sad, that our lives are filled with frustration. The fact is that a very small part of my life gets blown up into a very big part. Unfortunately, too many people see me as n

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did, took me in to their space, they took some of my clothes off, touched me in ways that were painful, and I felt that I had no choice in it. To me it's a form of sexual assault even though it was completely asexual. It's the power and domination that is part of the abuse. It's important for professionals to understand and acknowledge the power differential that exists between themselves and the children with disabilities they are supposed to be serving.

Michael: Norman, I am sure you realize that there are many people reading this who would say that the therapy procedures you describe are done to people with disabilities for their own good, after all it has a medical basis and it's considered a 'helping profession'. How do you respond to people who say that there is nothing abusive about what therapists do, that they obviously have only then

complexity of people just by acquiring an abundance of strategies. You gain the ability to deal with the complexity of people from the depth of thought. And many people avoid seeking depth of thought because they are too busy acquiring this endless library of disjointed strategies.

Michael: We certainly have a lot of strategies out there. Can you suggest any actions people can take to put them in some sort of perspective?

Norman: Read the stories of people with disabilities. Read the self-advocacy and disability rights literature.

Michael: If I am hearing you correctly, you are saying that there are no cookbooks, no easy answers about what is the 'right' thing to do.

Norman: That's right. It's the same as being a man in our male dominated society. At some point, as a man, I have to enter the world with fear and trembling knowing that I will, through my functions of power and privilege, do damage to women. I try not to, but I will. There is no recipe for me to say, 'If I do this, this, and this, I will be fine.' It would be nice, but it's not the way it is.

Michael: What do you hope professionals gain from hearing this perspective?

Norman: I hope professionals will recognize that the very nature of their role is an oppressor because of the massive power differential between themselves and the children they work with, or should I say 'work on'? The good news is there are things we can do.

Michael: Like what?

Norman: Everyone can start with themselves and draw on their own experiences. For example, as a man I need to listen to the stories of women. Not with my own arguments going on in my head, 'Yes, but, yes, but...' Instead, I need to listen to what it feels like to be a woman who fears for her own safety when getting out of a car alone in an underground parking garage. I need to really listen to that. I need to really hear that story rather than beating myself up with guilt or shame because men historically have dominated women in our society. I need to listen to that story in a way that overlaps with my own experience with fear as a person with disabilities. When a woman listens to my story about airline agents being overly condescending to me, rather than her feeling guilty and saying, 'Oh my God, I've done things like that to people with disabilities,' I would like her to listen to that story and remember a time when a car salesman or a auto mechanic was condescending to her: 'Yes dear, you wouldn't understand that.' Relating people's stories to your own experience is part of developing that depth of thought and reflection.

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Norman: First of all, I think all advocates have to be self-advocates. On Monday morning, the professional may not always do the best thing, but that is not the point. I think the question is not so much how can I guarantee to not do damage; the question is to recognize oppression, recognize the issues, and be willing to struggle with them.

Michael: What kinds actions can you envision as an out

African-Americans I can use analogies about used car salesmen, diets, or racial discrimination.