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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

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The information included in this article is based on a semi-structured interview conducted with Norman Kunc by Michael F. Giangreco on July 4, 1995 in Montreal, Quebec, Canada. The interview was tape recorded with Mr. Kunc's permission and was transcribed. The contents include selected portions of that interview and have been reviewed by Mr. Kunc to ensure that his opinions and ideas have been accurately presented in his own words.

Norman Kunc (pronounced Koontz) is a sought-after consultant and speaker on a wide range of educational, disability, and social justice issues. He was born with cerebral palsy and attended a segregated school for students with disabilities from the age of three until 13 when he was included in a general education school. Earning a Bachelor's Degree in Humanities and a Master's Degree in Family Therapy have augmented a lifetime of learning from his experiences of being labeled 'disabled' in North America. I have had the pleasure of being in the audience on a number of occasions when Norman has spoken, and each time I have come away with more to think about and act upon. His message is at times provocative and his insights are undeniable. Here is a bit of my afternoon with Norman Kunc.

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 classroom for a half an hour to an hour to get therapy, two to three times a week.

Michael: Could you tell me about some of your memories receiving those services?

Norman: First, I'd like to say that it's fitting that we are talking about rehabilitation issues on none other than Independence Day! To answer your question, I remember thinking that the physical therapy room was a very weird place.

Michael: Why do you say that?

Norman: They had all this strange equipment and weights and mirrors and bars. But the weirdest part of the physical therapy room was the staircase. There was this staircase with a handrail on either side but the stairs didn't go anywhere – they went right into the wall! The physical therapist would come up to me and say, 'Walk up the stairs.' And I'd say, 'Why? They don't go anywhere.' But she'd say, 'Never mind, walk up the stairs.' So, I'd walk up the stairs and nearly kill myself getting up there. When I got to the top the physical therapist would say, 'Good! Now walk back down the stairs.' I'd say, 'Wait a minute! If you didn't want me up here in the first place, why did you ask me to walk up here?'

Michael: Did she give you a reason?

Norman: She would say, 'You want to walk better, don't you?' I didn't know any better, so I said, 'Yeah.' And what I learned at that moment in life was that it was not a good thing to be disabled and that the more I could reduce or minimize my disability the better off I would be. When I was in segregated school, I fundamentally saw myself as deficient and abnormal. I saw myself as inherently different from the rest of the human race. The implicit message that permeated all my therapy experiences was that if I wanted to live as a valued person, wanted a quality life, to have a good job, everything could be mine. All I had to do was overcome my disability. No one comes up and says, 'Look, in order to live a good life you have to be normal,' but it's a powerful, implicit message. Receiving physical and occupational therapy were important contributors in terms of seeing myself as abnormal. Every part of my life, from the

minute I was born, told me that I was abnormal, whether it was getting physical therapy, going to Easter Seal Camp, or wearing leg braces at night.

Michael: How did you react at the time?

Norman: Well I wanted all those things, to have a good life – so I ended up declaring war on my own body. It was me against my disability; and my disability was my enemy. I was bound and determined that I was going to conquer that disability.

Michael: How did you propose to do battle with yourself?

Norman: I turned into a kid that physiotherapists only see in their dreams. If they wanted me to do ten repetitions of a certain exercise, I did 20. If they wanted me to hold a precarious balance position to the count of ten, I held it to the count of 30. I was determined I was going to get to be a valued person. And if that meant conquering my disability, so be it.

Michael: These early experiences happened when you were in a segregated school. What happened when you went to a regular school?

Norman: I thought I could overcome my devalued status as a person with a disability by being in the regular school. At first the school administration wanted to send me to a special class for students with physical disabilities in a regular school about ten miles from my home. I said, ‘The hell with that!’ First of all, I wanted to go to the regular school in my neighborhood because, for me, I guess that represented being valued. Secondly, I was offended by the stigma of being in a special class. I didn’t want all my nondisabled neighborhood friends to see me getting on that big blue bus for kids with disabilities. Why not just hang flowers around my neck with a sign that says ‘crippled’. I wanted to avoid all of that.

Michael: From what you are saying it sounds like there were a lot of professionals who saw your disability but didn’t see you as a person.

Norman: That’s true. If I had to describe myself to you now I’d say that I have an undergraduate degree in humanities and Master’s in family therapy. I got divorced, now I’m remarried and I live with Emma and two step kids. I like classical music and jazz. Having cerebral palsy is one small aspect of who I am: it’s part of who I am, but it’s not the defining characteristic that makes me who I am.

Michael: When people disproportionately focus on your disability, how have they treated you?

Norman: People make unwarranted assumptions about who I am as a person because of my disability. People in airports sometimes think I have a mental disability or treat me like a child. Sometimes they assume that I need their help. People sometimes assume that people with disabilities are asexual, have unresolved anger, are in denial,

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 nine-tenths disability, one-tenth person.

Michael: What has been the impact of these assumptions on your life and lives of other people with disabilities?

Norman: It makes you feel that you are not quite human. Almost like you have to earn your right to be human. In earning your right to be human, what do you get? Human rights! So when you are perceived as less than fully human, what typically are rights for nondisabled people become privileges for people with disabilities. It's like if you have a disability they are doing you a favor by letting you live in the community. As soon as I demonstrate I am mentally capable then I have earned my right into the community. I see this going on not only with people with disabilities but also around the whole issue of poverty. You have to demonstrate your merit. It's categorizing people as producers versus non-producers. When people see that I am intelligent and articulate, the message is, 'Even though this guy has a disability, he can make a contribution to society. Therefore we'll let him in!'

Michael: It sounds like what you have experienced is a classic example of what Marc Gold called the "competency/deviancy hypothesis" where the more competent the person is perceived to be, the more others will tolerate deviance in him. Of course, even that language, the term 'deviance', is so loaded with negative connotations.

Norman: I prefer to think of my disability as type of diversity rather than deviance or deficiency; my disability is just one characteristic or attribute among many that make me who I am. People do not need to prove their worthiness. Obviously, what we are talking about here is a human rights issue. We need to establish the unconditional and inherent worthiness of people regardless of what combinations of diverse characteristics they present.

Michael: Let me tell you a story from when did you start feeling as though your disability was a characteristic of your personal diversity rather than a deficiency?

Norman: When I was a university student. One night I was at this pub with a bunch of my friends. At one point, one of the guys started imitating my voice. It surprised me and I didn't like that he was doing it. So, afterwards I went up to him and said, 'Why did you imitate my voice?' He said, 'Because that's how you talk.' I told him, 'Hey, I'm articulating my words. I'm using my voice clearly. I'm not drooling. You imitate my voice and my whole show goes out the window.' And he said, 'Norman, why are you trying to be non-handicapped?' And that caused a categorical shift in my thinking. We talked for a long time that night and went through a lot of beer. Finally it dawned on me that I had the right to be disabled. And rather than seeing my disability as a deficiency, I began to see it as part of the inherent differentness among people; it was simply a characteristic. I came to understand that it really was no different from any other characteristic like height or weight or race or gender. So to say it another way, prior to

that incident in the bar, I saw myself as abnormal. You were the normal people, I was abnormal. You are all nondisabled, I'm disabled. I saw myself as categorically different from most of the human population. I was part of a group with all the other abnormal, deficient, broken, disabled people. Once that shift happened to me I said, 'Wait a minute, I'm part of the normal diversity of the human community. I'm normal in that I am diverse.' I began to think, 'Wait! Why has this small characteristic of who I am been used as a criteria to put me in a segregated school, to do this to me, to do that to me?' Everything that happened to me suddenly came up for evaluation.

Michael: Let me back up for a moment and ask you about your experiences receiving therapy services when you went to regular school. Did you continue to receive the same types of services to the same extent?

Norman: No, it pretty much stopped.

Michael: Who made that decision?

Norman: Well, I think the therapists actually made the decision because they thought I could do a lot of things, plus I wanted to stop anyway. Ironically, my speech improved the most the year I quit speech therapy.

Michael: It sounds like by high school you had strong ideas about what you wanted for yourself. Did those coincide with what your therapists thought was best for you?

Norman: I believe they *thought* they knew the best destination for me, but they were mistaken. The therapists usually saw the destination as one of two things. The more naive therapist often perceived the destination as being one of normalcy; to make me more valuable in society's eyes. So that was one destination. This may not even have been conscious to the therapists; I think it may have been unconscious.

Michael: Do you think people in special education and rehabilitation fields are professionally socialized and trained to think that way?

Norman: Yes, absolutely, but it goes beyond that. I think the field of rehabilitation is to people with disabilities what the diet industry is to women. We live in a society that idolizes a full and completely artificial conception of bodily perfection. This view of the 'normal' body tyrannizes most, if not all, women so that far too many women in our culture grow up believing that their bodies are inadequate in some way. The issue here is that I want professionals to think about the whole parallel between dieting and rehabilitation. That's why I always tell people with disabilities, 'Never do physical therapy with a therapist who is on a diet!' If she hates her own body, she'll inevitably hate yours!

Michael: You said there were two views. You talked about people who want to strive toward "normalcy," whatever that is. What is the second view you alluded to earlier?

Norman: Now there may be some therapists who say, ‘Wait a minute, I don’t want to make people more normal. I want to help them function better so that they can do more things.’ Although that seems to be a far more enlightened perspective, I still have serious concerns about it because professionals mistakenly equate functioning level with quality of life and that may not be what’s going on for some folks. Professionals say, ‘If I can help you function better, then your quality of life will improve.’

Michael: This is a very mainstream view. What are your concerns with that way of thinking?

Norman: If you think about it, nondisabled people often don’t equate the quality of their own lives with their ability to function in a certain way, so why apply it differently to people with disabilities? Rather than functioning level, I think most people would agree that the quality of life has to do with important personal experiences, feelings, and events, like relationships, having fun, and making contributions to the lives of other people. If you think about the most meaningful moments in life, they probably don’t have to do with your functioning level. I’d bet they have more to do with other things like getting married, the birth of your first child, your friendships, or maybe going on a spiritual retreat; they probably don’t have to do with your functioning level. Ironically, developing relationships, the opportunity to make contributions to your community, even fun itself is taken away from people with disabilities in the name of trying to get them to function better to presumably improve the quality of their lives. So I didn’t get to go to regular school and then I missed the opportunity to make friends. Why? Because professionals were trying to improve my quality of life by putting me in a special school where I am supposed to learn to function better. So they take away the opportunity for me to have friends and subsequently they actually interfere with the quality of my life.

Michael: Are you saying that people with disabilities don’t need to learn to function better?

Norman: No, for me I guess the key is the difference between what I call ‘ease of living’ and quality of life; many people confuse the two. Ease of living would be something to minimize the physical struggle, time, or energy that has to be expended in daily tasks. But just because life gets easier doesn’t necessarily mean that my quality of life has improved.

Michael: Could you elaborate on what you mean?

Norman: Sure. In our society I think that many people assume that if they make their life ‘easy enough’ that the quality of their life will naturally follow. So they focus on making their lives easier through earning more money, or getting a better house, whatever, assuming that this ease will bring about quality. Now, while I see ease of living as partially contributing to quality of life, I believe it’s overly simplistic to assume that quality comes from ease. Instead, I think many things contribute to a

quality life, like relationships, having a sense of belonging, fun, making a contribution, and to some degree, struggle itself.

Michael: In your presentations I have heard you talk about some very sensitive personal experiences you had receiving physical therapy and the impact it had on your life. Could you share some of those experiences?

Norman: When I was doing my Master's Degree program in family therapy, we did a section on sex therapy. We did exercises involving touch, comparing our reactions to those of people with sexual dysfunctions. Jokingly I said to my sex therapy professor, 'I can teach it, just don't ask me to believe it.' He said, 'What do you mean?' I replied, 'I hate being touched.' At that time I was involved in a sexual relationship where I could touch the other person, but I did not like to be touched. About four months later we were studying the side effects of post traumatic stress disorder, specifically how it related to victims of rape and sexual assault. As we reviewed the symptoms, like resistance of touch, lack of trust, and all the things they were talking about, I kept thinking, 'Yep, that's me.' Then I thought, 'Wait a minute? Why do I fit all these categories?' That's when I first made the association between sexual assault and my own life. My body carried the memory, and these discussions triggered me to think back to physical therapy.

Michael: Are you saying that you were sexually assaulted by a therapist as a child?

Norman: It depends on how you define sexuality. If you define sexuality as in a forced sexual act, then no. But if you define sexuality as it is being defined today in terms of physical space, in terms of your own control over your own body, then yes, it was sexual assault because the ramifications for me were sexual around the whole issue of touch. What I am saying is that the very practice of physical therapy in some of its historically common forms can have abusive outcomes.

Michael: Could you elaborate on what you mean?

Norman: If you think about it, from the age of three until the age of twelve, three times a week, women who were older than I was, who were more powerful than I was, who had more authority than I had, brought me in to their room, their space, their turf. They took off some of my clothes. They invaded my personal space. They gripped me and touched me, manipulating my body in ways that were painful - it hurt. Some of the exercises that were done in physical therapy were very painful, others were threatening. For example, there was the one where you are sitting or kneeling on the floor and the therapist kneels behind you and pushes you in different directions forward, sideways. The stated purpose of that activity is to improve reactive balance responses, but when I do this with nondisabled people as a training activity they find it enormously threatening when a person behind them is shoving them, especially when they never know what direction they were going to get pushed. When I was in school, I didn't know I had any other choice than to go along with it. So when you think of it, what did I have from the age of three up? People, women, who had more power than I

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 the best of intentions for people with disabilities?

Norman: I am only speaking of my own experience, but my response has to do with the whole issue of intent. Sometimes people get hung up on my ideas because obviously the therapist does not have the same intent as a rapist. Obviously their intent is different, it's positive, but there still can be a similarity of action and a similarity of consequence. My problem is that we can minimize the significance of the similarity of the action and consequences simply because the intent was positive.

Michael: So is part of your purpose to have professionals rethink what their intent really is and whether it matches their actions and the consequences that follow?

Norman: There is a difference between caring and competence. Many human service professionals assume that because they care for people their actions are inevitably competent. As soon as you challenge the competence of their actions, you're seen as questioning their caring for the person. It seems that competence, in their mind, is inextricably interwoven with caring. And they say, 'But how could you say I'm sexually abusing this little boy? I like this little boy. I would never do a thing to harm him.' You say, "Yes, I know you care for him and your actions may be cruel."

Michael: So what do you say to well-intentioned professionals who want to be of service to people with disabilities?

Norman: We've got to slow down. First of all, very often the temptation of many professionals is to ask, 'Tell me how to do it differently,' rather than saying, 'Help me think about this.' I hope people come to understand the complexity of the issues. That's what I'm concerned about.

Michael: Is there other advice you would offer to people who want to reflect on their practice to improve it?

Norman: I tell teachers and therapists all the time, 'If you really want to work on professional development, keep a journal.' Spend a half hour every night and write about what your students are doing. You don't gain the ability to deal with the

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.

Michael: So how does one avoid being oppressive when providing specialized services?

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 outgrowth of recognition of the issues, reflection, and struggle?

Norman: I can envision three different therapists reading this interview and in the most positive ways having different ways of coming at therapy. One may talk about it with her colleagues; another might change the nature of how she does certain exercises with a child; another might keep a journal to help her reflect on her work. All are relevant, but the important part is that they have listened to it and in some way tied it to their experience and then decided to take actions based on who they are as people, not as professionals, as people. I hope they will move forward conditionally, continuing to be cognizant that other stories may come up that will challenge them again; this is an ongoing struggle. Reflection, personal commitment, and the beauty of struggling with ambiguity is where real connections get made between people that raise them above the oppressor/oppressed scenario.

Michael: In that way will these professionals become better advocates for people with disabilities?

Norman: Let me back up a moment. My point was that all advocates need to be self-advocates. What I meant by that was I don't want professionals to advocate on my behalf believing that they now have this new found knowledge about what people with disabilities want. I don't want therapists to say, 'I've read ten issues of *The Disability Rag*' and then spout out all the politically correct jargon. No! I want therapists to tap into her experience as a woman, to tap into her experiences being in a position of less power, to pull that whole experience of women's rights and their own oppression into that therapy room. So when a case conference comes up where there is some issue being raised around intervention, around touch, or whatever, I want her to tie it to her own experience and can challenge things not just from the stories of other people, but from her own experiences.

Michael: Does that mean only people who have had some significant level of personal experience being oppressed can relate to the stories they hear from people who have been oppressed in other ways?

Norman: Do you mean, what do I recommend to you, Mike, as an able-bodied, straight, white, middle-class male? Listen well. I think people don't need to be members of an oppressed group in order to listen. I have met people of an oppressed group who can't listen. I think you are listening to my story more intently than many women have listened to my story. Sometimes I think I can get a short-cut with women or with

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

Michael: Any final thoughts?

Norman: Just listen.

We chose to include this interview for its powerful and challenging ideas, particularly about the personal impact of accepting diversity, rather than striving towards and enforcing standards of an artificial perfection. As with other chapters in the book, this chapter illustrates the damaging outcomes of seeing a person in terms of a single attribute or characteristic. Importantly, Norman Kunc calls for professionals to listen to the voices of others, and reflect on their own practice in order to transform it.

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