

# The International Journal for Direct Support Professionals

## Never Clocking Out: The Responsibilities of Direct Support Professionals Off Duty

By: Dave Hingsburger

How do you clock out of a civil liberties movement? The ability of direct support professionals to come to work and establish relationships with people with disabilities, to truly see the people they serve as – well – people is vital in order to be able to do the work they do every day. But what happens when you close the door behind you? On days off, you may feel really free from the job and from the responsibilities. You also may begin to feel conflicted.

You are now in a world which is relatively hostile to people with disabilities. You will have noticed, when you are out with someone who has a visible disability, that people stare and make comments or jokes at their expense. One direct support professional told me that, when she took a woman with Down syndrome shopping, the cashier would not check her goods out until she made a big deal about needing to put gloves on to protect herself. The woman with Down syndrome was humiliated and the staff was “so mad I didn’t know what to say.”

Beyond anecdotal evidence, the stories, and experiences we have, there is actual scientific evidence that, societally, we are not anywhere near where we want to be. Bullying and teasing, abuse and exploitation, hate crimes, and a legal system which is passive when the victim has a disability – all these things exist and have been proven to exist. This is one of those times where science and our experiences are one in the same.

But we are talking your off hours! But we are talking about things much bigger than us – what can we do? Well what can we do? Helen Keller a famous deaf blind woman said:

“I am only one, but still I am one. I cannot do everything, but still I can do something; and because I cannot do everything, I will not refuse to do the something that I can do.”

She may have been blind, but she could still see her responsibilities to do what she could, when she could, to make something better. She saw that most of us feel very small when it comes to major social ills and yet, even in that smallness, there was work that only our hands could do.

So, does that mean you have to “work” even when you aren’t at work? That you never get a day ‘off.’ No, it does not mean that, it means, every now and then, you will be in situations that need your voice, or your hands, or your resistance. And in those moments, you have a choice that you will need to make.

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## Safe Spaces

The idea of ‘safe spaces’ is one that has grown in recent years. It is the hope that you can be in a place and be safe there. Safe from prejudice, safe from the stares and comments of others, safe from active or passive discrimination. These spaces are rare, for all of us, they are rare. They are even rarer for those who have experienced marginalization or discrimination in the past.

Here’s the thing – if there is going to be a safe space, someone’s going to have to make it one, they are not naturally occurring; you can look your whole life for spaces where you feel safe and never find one. Safe spaces take courage. Bullies and ignorant attitudes tend to prevail and tend to feel ‘safe’ to practice harm and exclusion.

A DSP told me that she and the people with whom she worked would go to a food court in a mall near them; they all enjoyed going there with the exception of the fact that there were “a thousand acts of unwelcome” in that place. People moved away to other tables when they came in and sat down with the food they had purchased. People stared with hostility not curiosity. When children would wander over, they would be grabbed and yanked away. She told me that the people she supported only noticed the empty tables around them but never questioned it. Finally, she realized that this was the norm for them, this is what they had learned to expect in the world. She would speak up as staff, but her words were ignored, she was paid to be with them, her words were suspect.

She went back to that mall and ate at that food court on occasion when she was off; it was the closest mall to where she lived so she would be there, often with her family. She decided that now her words would have some weight, some heft. So, when she saw anyone being stared at or being the subject of the jokes of others, she would speak up. “At first I was nervous, but I wanted my kids to see me as someone who used the power she had to make the world different.” She said that her words seemed to shock people who never expected an ally to rise from the crowd to say anything. True, sometimes she faced anger, but mostly not.

Did the food court change? No, it’s never that easy, “But not around me, people behaved because they knew that I’d point them out, call them down. I always felt good inside because I did what I could. I conquered my fear, I used my voice.”

Getting personal for a moment, I know the other side of this. I am a fat man in a wheelchair, I am a magnet for the eyes of others, I am the target for a million little jokes. This has actually led me to avoid certain places, it forced me to make my world smaller in order to make my world safer. But I can honestly say that, 100% of the time, when I go out to a mall, or a movie, or a grocery store, or a walk through a park, I will experience little acts of hostility, not micro-aggressions but something bigger than that.

In all my years, I have never had someone do for me what that DSP did in the mall food court for others. Never. Until one day I was forced, by social pressure, to go to a place where I could predict that this would happen on a near constant basis. I tried to be away from people; I actually attempted to hide myself. Even though I’m big and was in my power wheelchair, which is bigger still, I’m hiding in a cloak room waiting. A group of teenagers, both boys and girls, spotted me and it started. Someone, an adult, noticed. Her back straightened, and she strode over to those kids and spoke to them.

I don't know what she said because her back was to me, but I did see the faces of the kids change to apology and embarrassment; they had been caught being ugly. They got out of there quickly. Suddenly, I felt safe.

No one had ever done this for me. Before or since.

Why didn't I speak up for myself? Because I am exhausted with this battle. Because I take it for granted that I kind of deserve this.

Years later, I remember everything about her. She may have forgotten what she did, but I haven't and I won't.

I have attempted to pay that back. I was in an airport where a young teen with facial differences was being stared at by people at the opposite bench. I just rolled my wheelchair up and parked, blocking their view. I said nothing to him, I just gave him a few moments respite from what he had been experiencing. Another time, I used my presence to stop a gang of preteens from bullying an elderly man with Down syndrome. In these cases, I am thankful that I had someone do for me what I needed to learn to do for others.

### What comes out of your mouth

We have lots of stories to tell. Get a group of direct support professionals together and the stories just pour out. All of us understand confidentiality, and all of us take care not to expose the lives of the people we serve, or more usually, a person that we serve. We get it. We are careful about it. We learn to tell our stories about our experiences with people with disabilities without using names and maybe even changing the gender, or we tell them as if they happened at a different place, a different job, than we have now. We are good at this.

On your off hours, or when you are in retirement, you will discover that people will be very interested in hearing your stories. Let's face it, compared to a lot of people, our jobs are very interesting. There will be a temptation to tell the most outlandish stories of the most significant behaviours that you have experienced from a person with a disability. It's easy to shock others and it's easy to make those stories funny.

But, and this is worth thinking about, what are you doing to the reputation of people with disabilities? Are you inadvertently feeding prejudice? If people, at their core, have a somewhat negative view of those with disabilities, aren't you just confirming their bias? Is there a possibility that your story, as funny as you see it to be, can become a story that changes its tone when told by someone else to someone else?

Let's look at it this way. This year Joe and I celebrated our 51<sup>st</sup> anniversary of being together as a couple. We are often asked what our secret is and, as much as I'd like to say, "It's me!" that wouldn't be true. We have some actual rules about our relationship that we follow. Early on, Joe and I had an experience that was pretty dramatic and made for a helluva story. I told it a few times, and then Joe said to me on our way home after a party where I'd told the story, that he hated that story, that he comes out the bad person in the story, that he wished I'd never tell that story again. And, as much as I'm tempted right now, I won't. Because I promised him all those years ago.

Later on, when I began to lecture, and to blog, and to write stories, I follow the rule that the two of us follow – we won't tell a story that embarrasses the other, we won't tell a story that portrays the other in a bad light. We just won't. And don't. This is confidentiality.

Tell all the stories you want but never make me look bad.

Think of that before you tell the story about work and a person at work to someone outside the field.

### Challenging Compliments Unearned

You all know what it's like. You tell someone what your job is and, suddenly, they look at you like you are a nun and begin to spout the usual: You must be so special; you must be so kind, and the big one: you must be so patient. In moments like this, it's easy to let that 'praise' flow over you. But wait, is it praise?

Think of what people are really saying.

You really must be special, and you really must be filled with kindness, and you must have boatloads of patience to be around 'people like that' – there is always a problem when we are talking about 'people like that.' AND the corollary is AND I'M NOT SPECIAL OR KIND OR PATIENT SO KEEP THEM NEAR YOU AND AWAY FROM ME. Those statements are a way of hiding hostility underneath the cloak of humility. They are giving themselves an excuse to exclude, and they are using you to do it.

Challenge it.

"Look if you are saying that it takes something special to be around people with disabilities, you couldn't be more wrong. Yeah, I have skills to support people, but I don't have a saint's heart to be in the same room with the people I serve."

And you do have skills.

Now it's time for the P part of DSP. You are a professional. You provide support. You want to be recognized as someone who has skills – not simply the qualities of a good babysitter.

### See Openings

You have heard it said about getting a job – it's not what you know, it's who you know. Let me tell you the story of Joey Moss from Edmonton. He was the brother of a woman that Wayne Gretzky was dating, and he met Mr. Gretzky when he was working at a bottle depot. Gretzky was impressed by his work ethic and recommended him to the hockey team manager who ended up hiring Mr. Moss to work for the organization. He is still there, long after Gretzky left, he's beloved by fans, he's had a tournament cup named after him, his face was on a mural in downtown Edmonton. All that's wonderful, but Mr. Moss continues to go to work every day and do a really good job.

This kind of initiative, something that occurred naturally was seized upon by Mr. Gretzky and a life was changed. In fact, more than one life; it is safe to say that Mr. Moss has directly affected the lives of many people over his years of employment.

So, if you are in a place or talking with someone, and you see an opportunity for one of the people you support to get a job, find a community, or be a volunteer, speak up and facilitate that happening.

### In Summary

On the day that this journal is mailed out, I will retire from my position as Director of Clinical Services at Vita, I'm still going to do a few days a month for them, and I'm still going to lecture and train while I still can. But, I realize I can never retire from my responsibility to the people who I have served, who have been in relationship to me in one way or another, who have given me the opportunity to make a living, enabling me to buy groceries and pay rent. I owe allegiance to those whose goals for community living seem simple, yet who face so many attitudinal barriers along the way. They can count on my allyship; I recognize their value and will ensure that through me, my words, and my actions. So will others.

### About the author

**Dave Hingsburger**, M.Ed., is the Director of Clinical and Educational Services at Vita Community Living Services. Dave lectures internationally and has published several books and articles in reference to disability. He provides training to staff, parents, and people with disabilities regarding sexuality, abuse prevention, self-esteem, and behavioural approaches. He has developed 'Disability-Informed Therapy' as part of his work towards creating safe spaces for people with disabilities to live and work.

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