

The International Journal for Direct Support Professionals

THE ZEN OF TOM

By: Dave Hingsburger

The following article was written by Dave in May of this year for our December journal. It is the last article he wrote for the journal – his gift to us, and we are honoured to share it with you.

So, I'm disabled. I am a wheelchair user. I can, for the most part, get around just fine but, admittedly, to do that takes all my concentration and all my strength. Obviously, then, there are times when one or the other aren't available to me. There is a particular infection that I get which levels me. Luckily, it happens rarely and, equally lucky, I have meds to take as soon as I notice it coming on. But that still will leave me dependent on someone who works with Joe to get me standing and to get me into the bed. The first time it happened, we had no choice but to ask our neighbour Tom for some help. He came quickly and, between Joe and himself, I was up and standing in no time. Not that it was super easy for them, I am heavy.

This happened again last week. I had had three bad falls, all in awkward positions where we had to call 911. To manage me up, it took six strong paramedics and firemen. I was reminded by them that my falls might have to do with a particular kind of infection, something I had forgotten. I went straight on the meds and waited until they took effect; I knew it would be a few days. Once again, we called on Tom and, once again, he came to help. Now Tom is not a social service guy, but he's a warm and friendly (and strong) guy, the best of neighbours.

This time, I really noticed how Tom helped me, and these are the things that make getting his help easier, without feeling somehow ashamed. He could teach a master class in helping; I'm hoping I can catch enough of the flavour of what he did to help you think about your approach to what you are doing.

1) He got it. Right off. Without anything being said. He understood my vulnerability, and he understood the trust that came with it. It isn't easy to ask for help for a reason, you are placing yourself, and your needs, and your weaknesses into the hands of another. The superpower that I don't have is being able to look into the heart of another; if I did have this ability, I would be able to trust without also having to have faith in another. Again, no words were spoken, but Tom's ability to make me feel comfortable and safe were remarkable.

Editors: Angie Nethercott, M.A., RP
Chanelle Salonia, M.A., BCBA



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I think of the people we serve. Do they feel comfortable with our support? Do they feel safe in our presence? How do we communicate our heart through the use of our hands? Our voices? Our approach to their needs? Are we so used to providing support that we no longer know what it means? Have we become numb to the dynamic of power that is implicit in our being the ‘helper,’ and they being the ‘helpee?’ Perhaps, since you are reading this, you can also take the time to figure out how you make people feel welcome and comfortable while you meet their needs? Maybe you can ask yourself if, in your interactions, people feel safe with you.

- 2) Leadership. Tom never assumed leadership. He never acted as if he knew better than me what living in my skin was like. Without being sycophantic and without losing his personality or sense of humour, he managed to defer to me in regard to what I wanted, what I needed, and how to go about it. He did this in such a natural way, that it was almost invisible to me. I didn’t notice him making an effort to listen to my voice, he just did. I didn’t notice him deferring to me with an expectation that I would lead the process of getting help. Sometimes the most powerful things that we do are done without fanfare, almost invisibly.

In preparing to write this, I spoke to a couple of people about the content and, interestingly, I got some pushback on this one. “I work with people who are non-verbal, how do you expect them to take leadership?” Firstly, and parenthetically, let me just say my skin crawls when I hear ‘non-verbal’ used to describe people with disabilities; I prefer ‘non-traditional communicators.’ Many so-called ‘non-verbal’ people often have a wide range of ways to communicate their needs and wants. As long as you see ‘non-verbal’ as ‘non-communicative,’ the person will be subject to assistance being foisted upon them rather than support being provided to them.

- 3) Tom just presumed that privacy was imbued in the help that he was giving. There was one part of the assistance that I needed where I wanted privacy, in that instance, it meant that Joe provided the help, and Tom stood outside the room. I asked for this the first time I needed his assistance and then never had to ask again. He understood that, even though I was vulnerable, I still needed privacy. He knew that we were neighbours, and he knew that his assistance made him a really good neighbour, but that didn’t presume that I would throw out all boundaries. I am an intensely shy person and want to honour what shyness means – in this case, it means that, though I am vulnerable, I recognize that there are things that my dependance doesn’t take away. It’s a signal to tell me ‘Hey Dave, you may want to watch this, you may not want to dismantle a major boundary.’

Privacy is one of the things that separate people with disabilities from their staff. Most of us in support-providing roles have a keen sense of privacy and, all the while that we are guarding our own boundaries, we are trampling down the boundaries of those we support. How often are privacy protests ignored? When someone with a disability says, ‘No’ to help getting dressed or undressed, a common response is “Well, it’s not like I’ve never seen one before.” And that may be true, but you haven’t seen theirs. Further, I was at a meeting discussing a man with a disability who was refusing to shower with the exception of one of the staff with whom he had no problem using the shower and accepting her assistance. This is NORMAL behaviour. It’s normal to want privacy, and it’s normal to feel uncomfortable to the point of refusal at the idea of stripping down in front of all the staff. Let’s go back to the first point, have you made the person feel safe with you, and if you haven’t, I say carry on with refusing to drop pants on command.

- 4) The first time that Tom came over, he brought something with him – his sense of humour. Even though I was going through a really rough time, Tom didn’t let me wallow in it. He saw the funny side of things and when he actually had to touch me to help me lift up, (the most vulnerable moment is often when you allow someone to physically touch you), Tom

made it funny, and that spirit of bonhomie leavened the air around us, and things just didn't seem as bad as I thought they were. His sense of humour kept his grasp gentle and his movements careful. People often think of a sense of humour as laughing and joking, but it's much different than that. You can see how anger makes our movements sharp and angular, similarly, you can see someone's good humour in how they move and interact with the world, you can actually see laughter right through to our fingertips. To tell you the truth, if Tom hadn't been someone with a sense of humour, I would not have been able to take help from him.

Do you think about your mood? Have you determined how it affects you and the people around you? Have you noticed that, when angry, you can become quite intimidating? These are the kinds of questions you need to ask yourself. I once had a woman with a disability in one of my workshops tell me that she was happy when her staff was happy because then she had a good day. Our moods are powerful things but, if we can develop a sense of humour while providing service to people at their most vulnerable, we can protect them from the dark side of our personalities, and our grasps that become a little too tight.

- 5) Tom was not alone in helping me, Joe was there, as he always has been, the whole time. He is my husband, but he is also an expert in what my support needs are. It was really him that Tom was coming to help. Joe and I, during this crisis, had many conversations about my going to the hospital where I could get support during this time of healing but, in the end, we decided that staying home was best for me psychologically. We knew, from before, that Tom didn't mind helping, so we called and asked him. He came in and immediately consulted with Joe about the best way to achieve the goals and then, under my leadership, he worked alongside Joe. The two of them discussed what the issues were and brainstormed the best way to provide me help that wouldn't hurt me; he brings fresh eyes to the situation and saw solutions that neither of us had considered. But there was no jockeying for power or for control. He never once questioned Joe's feedback or suggestions; he was aware that Joe knew what he was doing and worked with him without question or complaint.

Teamwork is such an overused and under-practiced figure of speech. I have been to many team-building activities and always left them uninspired because the person with a disability was really rarely thought of as a part of the team; they were mostly seen as a target of the team. And they always seem vaguely competitive in nature, which to me is antithetical to the idea of team. So, we enter into our jobs and are immediately taught that our voice doesn't matter, you're just the newbie, your ideas are met with 'tried it before, didn't work.' For a team to work, there has to be respect for the knowledge of those who have been around a long time, but also an openness to new ideas and ways of doing things.

- 6) When it's over, it's over. Whenever I have had to receive service or help from someone – from the visiting nurse to the specialist carrying out a test – I make a note to see how the interaction we've had has affected how I'm being dealt with. There are so many times that I feel respected at the beginning of service and disrespected at the end. I think that sudden disrespect is a result of power being added to the mix and changing everything. To help without diminishing another is a true art. Tom excelled here, I did not feel lessened by his help and support. I did not feel that his view of me shifted.

I have seen, time and time again, the faces change on staff who have had to get up to take someone to the bathroom. (None of that happened here with me, to be clear, this is just an example.) I have noted the change in demeanour when staff have helped someone get a coat on or get food from a buffet. I know that it's not inconvenience, it couldn't be; the staff are paid to provide these services, in essence, their time has been

purchased. I think there is an imbalance created by the roles we play...I help...I need your help. The question is how many of us can negotiate this imbalance and turn the responsibility of helping into the joyousness of helping?

Summary

I have just reread this article and, through it, Tom becomes like this saintly guy; I don't want to do that to him, and I don't want you to read it that way. Tom is just a guy. He and his wife, Colleen, live on the other side of the wall. They are both lovely people, caring people. But that's where it stops; Tom does the things I've listed naturally. The moment we make him 'special' for doing what he does, he loses his power as an example. "Well, of course he does that, he's a saint." That means that you don't have to aspire to do the things he does because you're not a saint. Tom does what he does because he hasn't been trained to do otherwise. He does what he does because his ability to assess a situation and then take action is really good. Those are things that you can do.

It's been four days since I have required any help from someone other than Joe. The meds have worked, and my strength is back. I managed through this time because of Joe and a little bit of help from a friend. Tom made it possible, through his willingness to help, to keep me in my home. I consider myself lucky to have the best set of neighbours across the wall. (And they are quiet too!)

About the author

Dave Hingsburger, M.Ed., is the former director of clinical and educational services at Vita Community Living Services. Dave lectured internationally and published several books and articles in reference to disability. He provided training to staff, parents, and people with disabilities regarding sexuality, abuse prevention, self-esteem, and behavioural approaches. He 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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