

Service, Support and Success

# The Direct Support Workers Newsletter

## The View from the Other Side of Care



By: Dave Hingsburger

*This issue begins volume four of the newsletter. We both are very excited to see how the newsletter has grown, both in the number of authors submitting articles and the number of readers subscribing. What started out as a small agency newsletter has grown to a publication read around the world.*

*We want to take this opportunity to thank you all for your support of the newsletter and for the lovely feedback we get wherever we go.*

*Both of us remain committed to bringing you more exciting articles full of practical advice. We'd also like to wish you and all the people you support a wonderful new year full of happiness and growth.*

*Dave and Angie*

It soon will be eight years since I became a wheelchair user. Sitting down, rather than standing up, changed my world in so many ways. But, I'll bet, not in the ways that you might think or predict. The aspects of having a disability that involve mobility – I've got that down, no problem, I know how to get around. In fact, when the wheelchairs, both of them, were introduced to me, I was taught how to best push the manual and how to mount a curb without falling over in the power chair. Some significant time was spent making sure that I was road ready, but no time was spent making sure that I was 'world ready.' No one mentioned that sitting down, that having a disability would mean that everything about my social status as a human being would change.

Some of this was unsurprising. I have worked with people with intellectual disabilities for decades now and I see how disability affects social standing. How disability gives permission for people to grab and yank, to yell and boss, to inflict opinion and to restrict wishes. I've seen how people feel free to demean and to mock, to bully and to tease, to trick and to make foolish. I've seen it. Depressingly, I've seen that, while these things mostly happen in the community and are performed by strangers, it's not always thus. Sometimes these things are done by care providers.

As someone who is now a care recipient, I've learned a lot about what it is to be on the other side of another's Paid care, and as much as we say 'we work for people with disabilities'... when receiving care, it never, ever feels that way. I never feel like the employer, I feel like the patient, I feel like the client, I feel like 'the bother.' There are those, however, who provide care in such a way that, while I may not feel like the employer, I don't feel like the lesser, I don't feel like a passive participant in the process.

I'm going to list a few of the things that those who help me, in a helpful way, leave me feeling simply helped and never lessened. I'm doing this because I want to learn from my experience and am going to resolve

to become a better care provider, a better and more helpful helper. Perhaps these might be ideas that you will find beneficial in your role as care provider and helper as well.

1. **Listen:** It's the simplest idea in the world, but it seems to be the hardest thing to actually do. I think, when you have a disability, people automatically feel like they are the experts in 'how to live' and 'how to do things' and 'how you should be as a disabled person.' Suddenly, it's almost like your voice isn't necessary and, in fact, your voice can get in the way of things running smoothly and things getting done. Yikes. I find that many non-disabled people have difficulty getting onto an elevator with me. These same people have no difficulty getting on an elevator along with a mom who has a pram (some the size of Saskatchewan) but, when they see me, their 'expert' switch gets turned on. They tell me what I should do, and they are never right. Sometimes it becomes the absurdist of absurdities when I keep trying to tell them that I know how to get on an elevator; please simply follow my instructions. It can be a wearing battle when fought over and over again.

And that's from the general public. When I need help from a professional, the hierarchy of their title and their role combined with their training and their sense of themselves as competent in service provision means that they have trouble involving me in the helping process. Sometimes I want my voice heard because, if they help me any other way than the way I'm asking for, they will physically hurt me. Sometimes it's because, if they do it their way and not mine, it will feel wrong. I always put my right sock on first, always. When I need help with my socks, as I sometimes do, I want the right sock put on first. The only reason I want it this way is that it will feel wrongly done the other way. I don't want to enter into my day feeling wrong.

It may not matter to you but it may matter a lot to me. It may do to follow some sage advice about listening that I got from a five-year old girl who said to me, with solemnity and seriousness, "Dave, you need to listen with your ears, and with your eyes and with your heart." I thought it was cute when she first said it; a day or two later, thinking about what she said, I came to think of it as wise. Many of us work with those who don't use words to speak; many of us also work with people who have such a history of punishment that their words are used to pacify while their behaviours are used to cry aloud – listening with our eyes and our hearts makes a great deal of sense when working with those who desperately need to be heard.

2. **Ask:** This may strike you as surprising, but even with tasks that I need help with every day, I want to be asked before I'm helped. There are three little reasons for this and one big reason. The little reasons are predictable: I may not want help at that exact moment; I am not quite physically ready to take help; I want help, but in a different way from the way I usually get it. The big reason? I want to feel some control over my life, over my body and over my help. I want to feel as if I am the primary decision maker – not you – and that my voice matters when it comes to my needs. This all may sound very selfish, and perhaps it is, but selfishness can be both healthy and necessary. I'm guessing you make your own decisions regarding your routines of everyday living and you don't think that it's selfish.

The fact that someone else is involved in my care can lead to me thinking, like I admit it did at first, that their needs as helper outweighed my needs as helpee. I started to organize myself, and inconvenience myself because I wanted to be seen as a 'good' patient. My goal has changed from being a good patient to living a good life – and that means making my own decisions about my care and support. So, ask me before helping me, every time.

3. **Inclusion:** Inclusion is neither a goal nor a philosophy, it's action. Imagine for a second that I'm being pushed to a meeting. The person pushing me sees someone that we both know and stops to chat. I could easily be involved in the chat and the social banter, but it's happening behind me. I am facing away from the chatter. I may struggle to turn my head around, or attempt to turn my chair around, but those can be cumbersome and difficult things to do. All that would have needed to happen is for the two people to step forward, just two steps forward so that I am able to see, hear and contribute. Conversations behind me or just off to the side of me make me feel like I'm simply not considered important enough to involve. I know because I've been told often enough that 'we just didn't think.' To that I say, 'Well, THINK!' And I say that because it matters. I see this same phenomenon with people who have intellectual disabilities who are left standing outside the circle of social interaction. It just takes a moment to realize that, not only is this not inclusion, it's kind of purposeful exclusion and, frankly, it's ugly. So the next time you hear people speak about the importance of inclusion, they aren't just talking about what goes on in the larger community, but also in the much smaller community of you and the people you support.

4. **Body Boundaries:** Disability isn't permission. I was astonished at – and this was probably the first thing that I noticed after becoming disabled – how much and how outright inappropriately people began to touch me. This doesn't happen now because I protest immediately at first sign of intrusion AND because I've learned how to throw off a 'don't you dare even consider touching me' vibe. At first though, because I was unprepared, here are some of the things that happened: strangers touching the back of my head, rubbing it affectionately – like they were petting a puppy, hands resting on my shoulder for an uncomfortable length of time, people smiling and attempting to rub my belly, people sitting next to me and putting their arm around my shoulders. Um. No. Um. Stop.

I have written and spoken and developed training packages about boundaries between care providers and people with disabilities, but never before had I experienced what that kind of touch felt like. It felt like I was no longer considered a man, an adult and an equal. It felt awful. Yet I still see people with intellectual disabilities touched by staff in ways that they would never touch another non-disabled adult. And frankly, it's creepy.

5. **Whose Time is it Anyway:** You have nowhere to be but with me. I was always aware that those who were helping me were being paid. No confusion there. What took me longer to understand was that they were paid to be there, with me, doing what needed to be done and helping when help was needed. Yes, it took me time to learn how to do things differently but what I didn't understand, after I understood that their time was mine, was the impatience that was shown. It was like they wanted me to hurry up and get it because there was some urgent thing they had to rush off to do. But there wasn't an urgent thing they had to rush off to do, they simply were there to be with me and help me learn how to be as independent as possible.

At one point, I admit, I snapped at someone – their obvious impatience was making it harder for me to do what I was learning to do because I was rushing to please them not going slowly to get it right. Sometimes when I'm out, I'll see someone with an elderly person in a store. The assistant looks either bored or rushed and clearly annoyed at the elderly person, their employer. I didn't get it. I still don't. You get to be out, you get to help someone, you are surrounded by things to look at and your only job requirement is to wait a bit; your day is 1000 times better at that moment than almost anyone else holding a job. Again – you have nowhere to be but with me.

6. **My Voice Not Yours:** I'm glad that you know that I drink – and this will sound odd – green tea - black. It's nice that you are paying attention. But you need to resist the urge to answer for me. Even when the clerk looks at you, speaks to you and invisibilizes (a word that people with disabilities all understand) me, hush up. I can speak for myself; I will not be treated as a “thirsty purse” – a thing with needs, but no humanity, no voice. No one will be surprised to hear that I have no difficulty in speaking up and demanding, politely usually, to be heard and to be included in the conversation. But many cannot. This is where you need to direct the conversation from you to the person you are supporting. It's powerfully important that you understand your job here.

Self advocacy begins, and is at its most basic, when someone gets to use their voice to state their needs or to make their own order in a restaurant or tea shoppe. The temptation you will feel, and you will feel it, is to assert your importance and demonstrating your helper role for all to see. Don't yield to the temptation; what may build you up will tear someone down. That won't be your intent, but it will be your responsibility.

7. **Allow Me To Gift You:** Please. Please. Don't brush away my words when I say 'thank you.' Don't say things like, 'Oh, you don't need to thank me, it's my job' or 'No thanks necessary' or 'What are you thanking me for? This is what I do' or 'No problem.' Don't say anything like that. I get that it's your job. I get that you are paid to help me. But this relationship we have is an odd one. While you are helping me, over the time that I need your help, we become, if everything is as it should be, people to each other. I know that giving you gifts is wildly inappropriate and would never do it. But I am able to give my thanks. If I give it, treat it as it is – a kind of personal acknowledgment of my gratitude for what you did, how you did it and for the way in which I have been helped or edified by the time we had together. I need to do this. I think, if you were honest, you need to hear it. It's something I can do. It's something I want to do. Please just say, in whatever form fits your style, “You're welcome.” That simple statement allows me to be, not just the taker, but the giver too. It makes me feel that my 'thanks' matters and, if that's true, then I matter too.

### **Summary**

Being a support recipient has changed how I provide support. I know what it is to be on the other side of care. I was lucky. I only received support for a short while after becoming disabled and then sporadically from others, other than Joe, my partner these 45 years. But, even when receiving support from Joe, these seven tips matter. For some reason, some incomprehensible reason, Joe puts his left sock on first. I shudder at the thought. It took a while for him to learn that, for me, it's the right foot first. It may seem odd that this would matter to me, but it did. And sometimes the discussion about the sock and the foot got a little louder than it needed to be. But now he gets the right, right. So, it doesn't matter who the support provider is – staff, parent, boyfriend – the tips above apply.

## Letter to the Editors:

All year I have enjoyed these issues. For the end of the year issue, this one is very special to me. I have worked almost 30 years in the field of ID/DD and I have been fortunate to have worked all across the country with various cultures. This was always one of my favorite topics..... When the institutions were closing in NY State and a group of us were going around and doing "screening" (for lack of a better word!) for people to move into ICF's, we met with so many different cultures. Our goal was to celebrate each one, even if that person was unaware of it. We met a man who was Jewish. We, as staff, learned so much about his faith and then taught this to him and had him attend Temple, etc. Although he had never been able to practice his own faith, he became quite involved. After about 8 years of his living in the ICF, we found his family and they came to visit. A real tear jerking story. The first thing his family said was how happy they were that he was able to remain within his faith and culture. I was so proud of the staff!

It was and still is a real HUGE deal to embrace the culture of others, and who doesn't like to do things with food???????????

Thanks so much for this special issue. Thanks for all of them all year.

Have a wonderful holiday season, and a great 2015!

Fondly and with great respect,  
Noella Simone

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## Answers to FAQ's about the Newsletter

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