

The International Journal for Direct Support Professionals

Determination, Strength and Power:

The Direct Support Professional and Making Social Change

By: **Dave Hingsburger**

A young woman with Down Syndrome is spoken of in disparaging, dehumanizing terms by a police officer in Canada.

In the United States, a young man with an intellectual disability was brutally beaten by a group of teens, slammed into the ground, punched in the face and stomped on.

A mother in England takes her daughter with an intellectual disability into her car and drives to an isolated spot. There she pours gasoline on herself and her child, and they burn to death. They had been the targets of bullies because of the daughter's disability for years. They reported it repeatedly, no action taken.

A little girl in Australia has to be watched constantly by her teachers because bullies in her school keep trying to push her down stairs. Her limited mobility doesn't allow her to protect herself or to stabilize herself if she were ever pushed.

Stories like these, from around the world, are appearing more frequently in local newspapers. Study after study shows that the social climate for people with disabilities in general, and people with intellectual disabilities specifically, has grown more hostile.

Editors: **Dave Hingsburger, M.Ed.**
Angie Nethercott, M.A., RP



Hands | Mains

TheFamilyHelpNetwork.ca
LeReseauaideauxfamilles.ca



Direct support staff have their own tales to tell. One mentions that when she was assisting a woman with Down Syndrome to shop, the clerk at the local store put on rubber gloves when putting the purchases through the till, not wanting to catch "r=traded" germs. Another tells of being with people with disabilities at a food court and having a whole table of diners get up and move to a table further away. Yet another mentions that when he accompanies the fellow he supports anywhere, "He is stared at constantly, just constantly."

You know.

We all know.

That society isn't always tolerant of difference. The examples given so far could easily be replaced with equally horrific stories of bullying and violence against people of different races, different faiths, different sexualities, differing experiences of gender, differing experiences of

mobility ... when it comes to humanity, you name it, and there is a prejudice against it.

Some of us know this because of our own experience of difference.

Some of us realize this because we love someone who is treated as less because of their difference.

But what can we do? What can any of us do? In order to answer that question, it's important to tap into that sense of social injustice you have when you see the people you serve treated unfairly, treated with disrespect, or treated in any prejudicial manner. To do that, you may need to tap into your own experiences with prejudice and discrimination. Recognizing that it hurts to be treated as less worthy and less valuable is a good place to start. Using your own experiences can help light the fire for what comes next.

What Comes Next? Action Plans

It is important to realize that we all have power, we all have the ability to take action, and we all have a responsibility to each other, disabled nor not, paid or not. We are part of a civil society and have a stake in making sure that Respect, and Recognition, and Rights are part of social discourse. So this newsletter is going to make three suggestions for personal action, three for professional action and three for public action.

Personal Action

- 1) Make Respect Your Foundation: We all need to spend time reflecting on who we are and who we want to be. Introspection should be part of every direct support professional's day. We interact with people; we have power which we can use or misuse in the lives of people. We have our own biases and prejudices, all of which require a rock solid understanding of our own values. Have you confronted the racism and sexism and homophobia and ableism in your decision-making process with the people you serve? Do you find one person's behaviour more frightening than another's because of the colour of their skin? Do you find one person's relationship more valuable because they love the 'right' person? Do you find it more acceptable for a man to be sexually victimized by a woman than a woman being sexually victimized by a man? We work with people and, because we work with people, and because disability knows no class, no colour, no sexuality, no gender – we need to be ready to stand at the intersection of disability and difference, ensuring that our decisions are fair and just, and that discrimination isn't part of how we do business.
- 2) Human Services Needs Humane Humans: The best part of working in human services is that we are human beings and that means we get to use ourselves as a resource. Your life experiences matter. When working with people, remember always that you are 'people together.' The use of the words: 'client,' 'consumer,' 'member,' and 'self-advocate' or the phrases: 'people we serve' and 'people with a disability' are necessary (though some more preferable than others) for clear communication. However, they can also distance you in your mind, your thoughts and, more importantly, your emotions from the understanding that you are 'people together.' The constant reminder that you are

working with another person who feels like you do, who has hopes like you do, who is easily hurt like you are, who doesn't like to be spoken to rudely like you do ... matters. It matters because, when the person becomes a 'job' or a 'task,' their bruises, on body and soul begin to matter less. This is never okay.

- 3) Discover “we-ness”: We are we. What part of ‘we’ don't you understand? Those two statements make it clear that while there are roles and responsibilities, while there are skills, and strengths, and needs, and vulnerabilities, there doesn't have to be a hierarchy. We are we. You are You, and I am I, and that's where we start. It is impossible to work in service to people with disabilities without a hierarchy in existence, and the pretence of equal power is dangerous. But, and it's a big but, that doesn't mean you can't work to eliminate as much of it from your interactions and supports as possible. Disability isn't permission to demean, or degrade, or devalue. Disability isn't permission to violate privacy, to violate boundaries, to violate trust. That may be the lived experience of many with disabilities but it doesn't have to be yours with the people you serve. We ... is a lovely word because it implies togetherness and camaraderie. It's a good place to start.

Professional Action

- 1) Develop Voice, Encourage Voice, Listen to that Voice: We need to move away from an understanding of our job as being one where ‘we speak for those who can't speak,’ ‘we advocate for those who can't advocate for themselves,’ or ‘we stand for those who can't stand.’ It is our job to support people with disabilities in speaking up for themselves in whatever way they can. One of the mottos I learned early in my career was, “Never do work for your client that belongs to them.” This is not a handy-dandy explanation for neglect, it's a challenge to get up and do some real work with real meaning. Even if it is to help other direct support professionals read the body language of someone you support – ‘no’ can be said with an eyebrow – you have changed their social world. You have increased their opportunities to use their own power. Remember this article is about making a difference in the world in which people with disabilities live. Sometimes that world may seem small to you but the impact may still be huge. But it's also about encouraging and developing the voice of people with disabilities when they encounter prejudice in public. Their voice in speaking to a manager. Their voice at a public meeting about bullying. Their experiences, their voices, their points of view need to be heard. This is one of several minorities that seldom gets the microphone when their lives are being discussed.
- 2) Model Respect: Here's where all that personal work shows itself. Here's also where inherent hierarchies come into play. Being respectful to people who are not familiar with the ways of respect can be more difficult than you might imagine. Being respectful to people who do not seem to have the power to challenge you, or whose voices may not be heard is even more difficult. For many people with disabilities, the bar is set so low as to what is considered respectful, you'll need to grab it and raise it high. As high as the bar is set for you. You speak respectfully to people whom you respect. So speak respectfully. You are patient with people you respect and willing to celebrate their growth – see it's easy. But it's easy to know what respect is, easy to say and more difficult to do.

There is good news: Respect is almost always, in every situation, with everyone, intentional. And because it's intentional, all you have to be is intentionally intentional regarding your words, your tone, and the decisions to ensure that they remain entirely respectful.

- 3) Counter Anti-Disability Sentiment: People with intellectual disabilities, although often targets of bullying, teasing, and other forms of social and physical violence, are not immunized from bullying or hurting others with similar disabilities. We sometimes are more worried about social and physical violence when done by non-disabled people than when done by one disabled person to another. This cannot be. It isn't the person – it's the behaviour. It's not okay. Direct support professionals need to work as a team to ensure that everyone feels safe in their home and safe when receiving service. This may mean that you have to make referrals for behavioural services or counselling services for both or either the victim or the bully. More than that though, counter the use of slurs against any minority, including those of us with disabilities; don't let them go unchallenged. Ever.

Public Action

- 1) Discover Your Spine: Reach round, touch the center of your back and get reacquainted with your spine. You are going to need to become best friends. Speaking up is a difficult thing to do in any situation. But being ready to counter someone who uses racist, sexist, homophobic or anythingelseist language is a difficult thing to do. We know that people with disabilities are increasingly targets for hate, for violence and for social exclusion. But these are not things that they experience exclusively. We also need to remember, though publicly disability almost always has a white face, disability does not discriminate, and disabled people, as a people, are as diverse as the rest of the population. You cannot, therefore, be pro-disabled and racist at the same time. The term 'intersectionality' means that people can be at the intersection of race and disability, gender and disability ... I won't continue but, if I did, there would be enough intersections to make a beautifully diverse and inclusive city. Mocking disability is wrong. Blackface is wrong. Exaggerating someone's accent is wrong. Standing up to it is difficult, and you may be singled out, but that's part of the job of being human. By being human in human services, it becomes a heightened issue because of what you see on a day-to-day basis.
- 2) Use Your Voice: It's funny that some direct support professionals who are really good at supporting the voice of the people they support find it really difficult to use their own voice. They can be wonderful advocates for someone with a disability but have a great deal of difficulty advocating for themselves or for things they believe in. It takes practice, but you will get better at it. There is a kind of moral compulsion to be clear about our desire of respect for all; our voice breaks the silence that so often exists around bullies and bigots. Martin Luther King Jr. said, "Our lives begin to end the day we become silent about things that matter." There are many ways to use your voice. If you are in a situation where you think that the person who needs to hear you is in a corporate office, not at the till in front of you, write a letter. Don't worry so much about anything more than a clear message of why you are writing. Letters make a difference. They do. Trust me, they do. Using your spine and your voice will change your life in so many positive ways –

but they will also change the world around you. People never, ever, ever use bigoted words around me because they know I'll speak up. I don't know what they do elsewhere but, if I make the world around me safer, I've done my job.

- 3) Be Careful, Be Aware: There are those out there who want to feed the beast of hatred and bigotry in you and will provide you with articles and infographics that either twist true or are simply false. They play to our weaknesses – the residual racist you, the residual sexist you, the residual bigot that you fight hard not to be. We all have to be on guard against the years of programming that we've all had which has led us to fear each other. When you receive something on Facebook that riles you up and seems to be calling you out, inciting you to prejudice, check it out. Recently a meme went around Facebook pages in Canada about refugees and old age pensioners. It suggested that refugees get more money and more help than Canada's elderly population. It was completely untrue, but it whipped up anti-refugee sentiment. You need to take a moment, and use Google to help you discover what's actually true. Don't let others manipulate you. Don't forward a post promoting hatred without checking it out. Don't make the world more dangerous for those who are different.

Private, Professional and Public Action

- 1) Words. Words. Words: Be really careful about the words you use in your own mind, in your conversations at work, and when you talk about your work in the community. Firstly, really work to get rid of the language of ownership: My guys. My kids. My girls. My boys. Yikes! When you think of people this way, when you talk about them with others at work this way, when you use this language in describing your job, you are doing damage. These words lead to a 'belief' about people with disabilities that they are under the ownership or dominion of others. Yeah. They do. The people you serve as adults need to be spoken of as adults and as their own people, not those corralled and put under the control of others. People are simply people, a disability doesn't erase 'peopledom,' but it's a helpful descriptor of who we serve. People with (intellectual) disabilities, (intellectually) disabled people – your choice about how you describe the people you serve. Disability isn't a word to be afraid of using. Some of the people you work with don't like the word; there has been a lot of shame attached to it, so don't use it around them. But in general, the word is the preferred word of the disability movement. #Disability Say the Word. Beyond that, don't describe people with disabilities in a way that plays into stereotype and false sentiment: "They are all so trusting!" "They are so innocent," or alternatively, "They are so dangerous." "They can be really violent." You can see the problem with these statements can't you? It's the word 'THEY.' There is no THEY. People with intellectual disabilities are all individual people with individual lives who have individual strengths, weaknesses, talents and issues. Encouraging the idea that people with disabilities are a monolithic group of smilers is just weird.

Being human in human services allows you to see the best and the worst in the world. It will allow you a glimpse into the kinds of everyday prejudices that people with disabilities have to endure. Seeing that can motivate you to look closely at yourself, to look closely at how you provide service and motivate you to make social change. That is, in and of itself, kind of awesome.

It's work, it takes time, but it's awesome. We are called to be our best selves and with that comes a responsibility that can reach out and change the world around us. And there are a lot of us. So the potential impact is immeasurable. As a direct support professional, you have Determination to see the right thing done, the Strength of will to make it happen, and the Power to change, if not the whole world, at least the world around you. Again. That's kind of awesome.

About the Author

Dave Hingsburger, M.Ed., is the Director of Clinical and Educational Services for Vita Community Living Services, and is a well-known speaker, writer and consultant on the topics of disability, sexuality and self-advocacy.

Answers to FAQ's about the journal

- 1) The journal is intended to be widely distributed; you do not need permission to forward. You do need permission to publish in a newsletter or magazine.
- 2) You may subscribe by sending an email to dhingsburger@vitacsl.org
- 3) We are accepting submissions. Email article ideas to either the address above or to anethcott@handstfhn.ca
- 4) We welcome feedback on any of the articles that appear here.

