

Service, Support and Success

## The Direct Support Workers Newsletter

### Resolved: Change the World

By: Dave Hingsburger

New Year's, for many, is a time when resolutions are made and, usually quickly thereafter, broken. Even so, some do succeed. Some make a decision, stick to it, and change their lives. This issue begins our 5th year of publication and, in talking about it, Angie and I decided to mark this milestone by telling you three stories. Each of these stories will illustrate how we all, in our work with people with disabilities, can, if we choose to, change the world. We can have an impact that is much greater than we imagine and, if we put our minds together and act as a group purposefully, what we achieve can be nothing less than world changing.

#### **The Power of Simply Being:**

Joe and I were shopping in ASDA, a large grocery store, in Liverpool many years ago, and we went for a cup of tea after shopping in their little cafeteria. We had just taken our seats beside the window which looked as if it were weeping for want of sun, and we began chatting. I noted being noticed by some of the others who were there having coffee, reading the paper or catching up with friends. Then, a fellow with a really significant physical disability came into the room accompanied by his support provider. His chair was complex and was steered by breath; his body, was shaped atypically and asymmetrically and the chair cushions looked like they were made by a high street tailor.

The support provider got in line and got them each a coffee and then sat down beside the fellow in the chair. Those in the restaurant who had thought me different, reevaluated their point of view, and shifted their gaze to the man in the chair. I have noticed something odd. In general the more people admire the technology of a chair the less they value the person using it. I was growing uncomfortable because many people were openly gaping as they were watching the fellow in the chair drink his coffee with the support worker's assistance.



**Hands**

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### **And then it happened.**

They began to chat. I couldn't hear, no one could hear, what was being spoken about because they both spoke very quietly, but they chatted and they laughed, and soon it was unremarkable to see a coffee cup make its way up to either set of lips. They were having such a good time, enjoying each other's company, savouring the coffee that something more magical than even Disney could manage happened. Suddenly there were just two guys talking. The sheer normalcy of the situation challenged every prejudice and preconception that anyone would have about disability even, as in this case, significant disability. The support worker's ability to demonstrate, on such a public stage, that respect and relationship can coexist with the reality of disability was as much a political act as it was an act of support.

I don't know if the staff realized what he was doing – often those who are extraordinary at their work don't – but I hope he understood that the two of them there, at that moment, doing what they were doing was a direct challenge to every person sitting in that place, every person who thought that staring was the appropriate response to difference, every person who had put down their coffee in disgust, every person. That staff was supporting a person with a disability and engaging in community change at the same time.

I am telling you this story here, and it's preaching to the choir, but imagine all those folks in that coffee shop going home that day. Imagine the story they had to tell.

OK.

Pause.

Now imagine the story they would have to tell if the support worker had come in, got coffee, and grudgingly lifted it up annoyed because it interfered with typing a text on their phone.

We have choices.

We can change the world.

Or not.

### **The Power of Staying Silent**

I had been working with a small group of self advocate facilitators as part of my ongoing work with an agency in the States. One of them and I got into quite a heated argument when I took on the 'I speak for those who can't' sentiment. She had said that she worked with a woman with Down syndrome who was so incredibly shy that she never spoke up for herself. A couple of times shopkeepers had short changed her and she proudly talked about going to the store with the woman and talking to the shopkeeper or the manager or whomever; the woman with Down syndrome standing shyly silent, and embarrassed throughout. I said that this was grandstanding not advocacy and we had a battle royal.

A couple of weeks later, I was able to meet the woman with Down syndrome and she was indeed shy but she had a way of carrying herself that demonstrated a clear message of personal pride and purpose. In meeting with the facilitator, who had calmed down, we talked about teaching advocacy rather than doing advocacy.

### **Here's what happened.**

They were in the local pharmacy where the woman with Down syndrome had picked up a few things for purchase. She was waiting in a short lineup of people for her turn. By the time she got to the front, the line up was much longer. She watched as her items were tallied up and then she had change dumped into her hand. She took a breath, looked at the teller who was reaching for the next person's things, and spoke.

"Could you please count the change out for me," she asked in a quiet but firm voice as she handed back the change, "because some people steal from me?"

The staff told me that the second part of the statement was not part of the training; it was simply an added on fact that explained the purpose of the change. The teller glared at her but, before she could refuse, a man standing much further back said, "Count her change out, we've all got time." The lineup waited for the few seconds it took for the change to be counted out. The woman with Down syndrome thanked the teller and moved on.

OK.

Pause.

Imagine the story that people are going to go home and tell. They are going to tell a story of a strong and powerful woman with Down syndrome who knows how to speak up, who knows that people take advantage of her and who knows strategies to deal with dishonesty. I imagine there might even be people there in that line up that need to learn to speak up themselves – lack of self advocacy skills isn't just an issue for people with intellectual disabilities! She could have made a huge difference in the life of another person. All this because the staff understood the power of silence – hushing up so that another, a less used, voice can be heard.

Compare this to what the story they would have to tell if the staff had brought her back and made a huge fuss over her being short changed. They would all wonder why she's allowed out by herself and think about how awful it would be to be so constantly vulnerable. They would have their misconceptions about disability reinforced.

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Or not.

## **The Power of Passion**

An older man with an intellectual disability moved into an apartment building where he received minimal support for issues around budgeting and other more routine matters. He had dreamed of his own place for a long time, starting when he was young and on the ward of a large provincial facility. After a couple of days his support staff noticed that he seemed tense and edgy. On investigation she found out that he was being bullied by some and aggressively ignored by others. People complained about having him in the building even though he was a good neighbor; he was then and is now a kind polite man.

Things didn't get better but they didn't get worse; the bullying was almost exclusively name calling and jokes at his expense. He didn't fear any physical violence. He had wanted an inclusive life in the community but it felt to him like he was living, completely isolated, in an unwelcoming environment. That spring, on the urging of his staff who strongly supported his idea, he approached the superintendents of his building, people who had been very supportive of him, and asked if he could grow flowers along the front of the building where they got lots of sun. They loved the idea and said they would purchase what he needed.

### **He began to garden.**

The staff would time her hours to come by when he was working outside and would garden with him for a while before going in to do other work with him. The two of them laughed and chatted and he taught her about gardening. Soon other frustrated gardeners were showing up and joining in with the chatter and helping out with the work.

Within a few months the seeds were sprouting but a community was full grown. Bullying of any form stopped because people wouldn't have it. He was a valued member of a group of people who took pride in where they lived.

It may not be as immediately evident here what the staff did. But what she did was wonderful. She encouraged him. She backed him up. She joined in with him. She never took leadership. She never took on battles that weren't hers. She allowed him to find a way to make the community his. She supported him through the bad times and into the good.

OK.

Pause.

Imagine how he is being spoken of, by his fellow gardening buddies. Imagine how their view of someone with a disability had changed. They went from silent acceptance for some and active participation for others of bullying and teasing to outspoken proponents of respect. This is enough to tell you that they had changed. And that their change led to action. The ripple effects of this will go far and wide.

Now imagine if the staff had not encouraged him, had told him that he's better just keep to himself. What if they had been defeatist and said that the superintendents would never go for it so don't even bother trying. What if they just did the budgeting and got out – without thinking about the life he was living. There would be no story to tell.

We have a choice.

We can change the world.

Or not.

## *Happy New Year*

Both Angie and I wish you the happiest of new years ... we know that many of you will have other new years at different times of the year ... we wish you the best on those as well. We hope that this article will help you remember that you can change the world, just by doing what you do in the best way you can do it.

***And remember ... we have a choice.***

**Editors:** Dave Hingsburger, Vita Community Living Services and Angie  
Nethercott, North Community Network of Specialized Care, Hands  
TheFamilyHelpNetwork.ca

### **Answers to FAQ's about the Newsletter**

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