

The International Journal for Direct Support Professionals

Summer Days Summer Ways: How Direct Support Professionals can make Summer Happen for People with Intellectual Disabilities

By: Dave Hingsburger

I was sitting on a patio in my neighbourhood with my husband. It's a favourite summer spot of ours – more on that later – as we like sipping tea, and watching the crowd go by. This is right outside of a coffee shop, obviously, and we see the parade of people going in and coming out. Something happened that day that made me really need to write this article. I saw a young staff I know accompanying a woman with a disability whom I also know approach the shop. I know that they saw me, and I wasn't offended that they didn't wave. In fact, I was pleased. I had once worked with the woman with a disability as her behaviour therapist; she's good with greeting me in places where people all know who we both are, but outside is outside. She thinks, and she's right that, if we greet each other outside and anyone knows what I do for a living and, "Everyone knows what you do Dave," they will know that she was a client of mine. Fair call.

As they walked up to and into the store, people were fairly silent but, once they were in, talk erupted around me, as they discussed two topics:

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First, they were horrified by what the young woman (she was in her early thirties) with a disability was wearing. They thought that it didn't suit her body, it was too tight, it was too revealing, and yes, it was too sexy for a woman like that. The judgment flowed from both genders around me. Her tight tights and the exposed flesh left by a small top was an, "insult to the eyes" one said, and another commented that, "Women like her shouldn't be dressed up like that."

Secondly, they were furious with the staff for "letting her go out like that" or "dressing her up like a tart" (changed the word there). Staff apparently, in their view, need to make sure that people they support are "clean, tidy and presentable" when they go out. Let's begin this summer issue of the journal with this point:

Disabled bodies are owned by disabled people and don't need anyone's approval.

There are two issues at play here. One: the young woman isn't runway model thin; two: she lives in a disabled body. Not one person spoke up to say, "Who the hell cares what she looks like in those clothes?" Don't you notice that, if you look at her, you can see she feels beautiful? And that's all that matters folks. That's all that matters.

Body shaming of people with disabled bodies knows no ends. A woman with cerebral palsy reports, laughingly, that she's a woman out of her time because, when she goes out in her bikini, people seem to need an ancient vomitorium to be somewhere in the vicinity. She knows how people react to the sight of her, and she doesn't care. She owns summer too.

She owns summer too.

You know how you get a bikini body? You put a bikini on your body. There – you have a bikini body.

It is no secret that I am a very fat man, I bought myself some really cool, as in not hot, shirts of a really light material. I never wore them. I bought them but never wore them; summer came and went, and they hung in the closet. I wore one last week on a hot day, and it was cool. I realized that people don't stare at me because of my fashion choices; they stare at me because they are rude.

Think of a patio full of people freely making comment on a woman with an intellectual disability, and her clothing, and her right to wear that clothing. **AND HER RIGHT TO WEAR THAT CLOTHING.** The problem here is that they refuse to acknowledge that she owns her body, and that their opinion doesn't matter.

Point one: Summer calls for summer clothing. Go shopping – buy what someone likes. Keep your inner critic silenced. You may find yourself with the same kind of prejudices as those expressed on the patio: it's too sexy, it's too flirty ... get over yourself. It's time people with disabilities had a choice in how to clothe the bodies they live in. That young staff who was roundly criticized by the people on the patio was doing an amazing job. It must have felt good too because she saw how the woman she supported was feeling, and she knew that's what matters.

Let's move on. I received an email from a direct support professional just to tell me a story. He had just returned from taking a fellow he supported to a local farmer's market to pick up some eggs and vegetables. He had never taken him to the farmer's market because the house where the man lives shops at a local supermarket. They were there to pick up something quick, forgotten in the weekly shopping. I'll quote from the letter: "We walked around the market and the veggies were all displayed and the colors all were beautiful. It was like a feast for the eyes. He saw all sorts of things he'd never seen before and asked me lots of questions. The woman working one of the stalls heard his questions and came over and they had the longest chat. I just stood by and watched. I shouldn't have been surprised my local farmer's market is very friendly with loyal customers who treat each other like family. It was a perfect thing to do on a summer's day."

The fellow writing me the note was writing about finding community, but he was also writing about exploring and experiencing summer. People need to feel the seasons, and there are all sorts of ways of doing that. Think of summer spots: beaches, parks, swimming pools. Okay, you can do better than that: garage sales, outdoor antique markets, celebrations in the park, fireworks, hayrides and, of course, cow bingo.

There are some activities made for a summer day trip, that are perfect for making a day feel different, that are what people in the community do to enjoy the season. Sometimes, if you want to know how to ‘do’ community living, just do what people living in the community ‘do.’ That’s high powered advice you got here for free!

Point Two: Summer needs to feel like summer. Get out; go do what people do in summer time. Support your local farmers by buying local produce; you might meet someone who becomes a new part of your community. Go to places where people go. If it’s too crowded there, then get there early. You know that when a place is crowded, it’s a place where people go to experience summer.

When I was a direct support professional all those years ago, I was working with another fellow on the morning weekend shift. We were there early, and the house just felt so confining. Summer was in full blast, and we both wished we could spend the day outside, but the van was broken down, and no activities had been set out for us. When people got up, and we started to think about breakfast, we realized something. The house had a back yard. There is a wonderful summer resource. We decided to have breakfast outside. Everyone had fun setting things up. It was fun to break with routine. We sat around the breakfast table talking and laughing for a very long time. There was no rush. It was the weekend, it was summer, who cares if dishes didn’t get done right away? Who cares if we just sit and relax and just spend quiet, quality time outdoors?

Shaking up routines – a little bit like adding slices of cucumber to a jug of cold water in the fridge – is fun. Even better if you bought it from the farmer that grew it. It’s a bit different; it’s a bit of summer.

Picnics and barbeques bring on a sense of summer as well, and they are part of many people’s traditions. I recently went to a barbeque and had my veggie burger slathered with barbeque sauce, fried on the grill, and it tasted of my childhood summers when we went camping.

Point three: Summers need to feel a little more relaxed. It’s a chance to take the indoors, outdoors. For us, as Canadians, summer can be a couple of days long; we don’t want to miss it. Find a way to get outdoors, make an opportunity for people to feel breeze on their skin. Slow down, remember the lyrics to the song Summertime: Summertime and the living is easy.

Last year I was at the boardwalk, in the summer, sitting and chatting with a friend. I noticed two young people pushing two elderly people in their wheelchairs. The two women in the chairs were looking quite unhappy, and were trying to get the attention of the women pushing the chairs. They, however, were talking, laughing, and enjoying the walk. I felt compelled to call out. Now, I could have told them what I was seeing, I could have spoken about boardwalks and wheelchairs from my own experience. But I didn’t. I’ve learned from self-advocates that I need to hush up, and let them do the talking. I simply said, “The women you are pushing are trying to get your attention.”

What happened next was brilliant – the two women were mad; they'd been brought there as a surprise. They could have told the staff that boardwalks aren't fun for them because every board jars the wheelchair, and they get tossed around. They made it clear that they had been trying to get their attention since they arrived, and that they were angry about the fact that staff who were supposed to support them didn't even check to see if they were enjoying the surprise.

Lesson 4: Because you like it doesn't mean the people you support will. It is always important to include people in the decision-making process. One staff told me years ago that she realized in a flash of self-realization she typically took people on 'surprise' outings when she thought they'd say 'no,' and she wanted to go. I thought that a brave admission on her part. It's what makes her a direct support *professional* because she was willing to learn about herself and her motivations at work and make changes.

It's not about you.

Help someone discover what they like about the summer, where they like going, what they like doing, and allow people's voices and choices to be part of the process. Don't inflict summer on them, explore summer with them.

Summer has its dangers. I learned this my first summer as a wheelchair user when I sat down in my wheelchair, which had been in the trunk of my car on a hot day for an hour's drive. I got out of the car, straight into the chair, and burned myself badly. Wheelchairs are wonderful and freeing, but they are also made out of metal, and metal gets hot, and hot can hurt. Think things through and prepare, leave early so the chair can cool down after being unloaded. Don't let an empty chair sit in the sun if the person using it is sitting on the grass. Cover it with a blanket or put it in the shade.

Make sure you review people's allergies to bug bites and bee stings. Check on allergies to various foods and drinks associated with summer. Don't just rely on your memory – check – this is where it gets to be life and death. Take people's EpiPens or whatever it is they use to keep safe if they do accidentally eat something they shouldn't, or get stung unexpectedly.

Prepare picnic food that doesn't morph into poison in the sun. Sunscreen can't be used as a salad dressing so maybe potato salad isn't the best option.

It's simple really; it's all the stuff that you do with your family to ensure that everyone is safe. Do all that at work.

Summary

Summer is such a wonderful time of year; it's something to be enjoyed but summer doesn't just happen. You know all those wonderful memories that you have from summers in your youth. Someone did a lot of work to make those memories possible. Your parents planned summers. Your parents thought through the days, the activities, and the traditions they wanted to pass on. It all seemed easy to you but, ask your parents, it wasn't easy – it was fun, but not easy.

If you can spend this summer making new memories for people, memories like you have, that's a great way to spend your work day. I was talking with a woman with a disability the other day who was still mourning the loss of a staff she'd had for years. She was reminiscing about a summer trip they'd taken to a cottage, and was laughing about the first time she got into a row

boat. She was over 50 years old, and the memory made her laugh until she cried. That staff had made a memory for her about a summer, about a boat, about a lake but also about the staff that made it possible. To be remembered in such a profound way is a reward that I'll bet the staff never thought about, but it's one she got. She made a difference and, in doing so, she will live in memory for a long time to come.

About the Author

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