

Service, Support and Success

The Direct Support Workers Newsletter**Um, It's a Human Thing...****Being Careful about Diagnostic Overshadowing for People with Disabilities**

By: Dave Hingsburger

It's odd that it needs to be said, but it needs to be said: Sometimes people with disabilities are just people.

It's also odd that we need to remember: People are affected by what goes on around them, what is going on inside of them and how they experience the world they live in.

And, again: People with disabilities live in the same world and experience the same things as everyone else.

OK, now that we have that out of the way, let's look at a term that's been around since the early 80's: "Diagnostic Overshadowing." What that means is that someone who has an intellectual disability will have almost everything attributed to their disability. You've probably heard Diagnostic Overshadowing in the discussion of the behaviours of people with disabilities. Like me, you may have even done it from time to time.

A child of three with Down Syndrome throws a tantrum when another child steals her toy – "They do that those Down Syndrome kids."

A woman of 20 with an intellectual disability gets frustrated and yells for people to listen to her when she's not being listened to – "They do that those types of people."

A man of 65 gets frustrated that an 18-year-old staff tells him that he can't watch what he wants on his own television because it's not age appropriate – "They have short fuses those people do."

People who live with differences get used to being treated differently and seen differently. This can vary from the kind of stereotypical thinking shown in the little examples above to more serious problem thinking from staff and clinicians who serve people with disabilities – diagnostic overshadowing may focus on someone's disability and ignore the environment or the situation that the person is experiencing.. It's important to understand that all humans respond to what goes on around them. This isn't exclusive to people with disabilities at all. Office workers frustrated by an overbearing supervisor don't seek out behaviour therapy because they mutter curses under their breath every time they have to go meet with their brute of a boss. Bus riders don't seek out hours and hours of therapy when they get anxious and fearful when the bus breaks down. People in these situations recognize that their feelings and their behaviour are tied to the events that are happening in the present tense. These are normal human reactions to normal human experiences.

Getting Back To Normal

We need to get back to normal.

Let's take a look at some of the emotions, symptoms and behaviours that occur when people experience a variety of human situations. Everything you are about to read comes from studies and reports about the effect of living on regular, typical people. None of the material is based on a disability at all. The point is ... hey ... it's normal. Sometimes it seems like we want to 'pathologize normal' in people with disabilities.

Sensory Overload: Turn That Bloody Radio Down!!

Sensory overload. How many times have you heard this referred to for people with either intellectual disability or autism? It has almost become synonymous with disability has it not? Well, are you aware that any human being can suffer from sensory overload? Let's take a look at what it is: sensory overload occurs when one of your senses is over stimulated. Now let's look at a partial list of how typical people react to sensory overload:

- Irritability
- Shutting down
- Avoids touching or being touched, closes out sound, shuts eyes
- Avoids eye contact with others
- Reacts to small changes in noise or lights or smell
- Loses the ability to focus
- Has trouble with social interactions
- Fidgety and restless
- Angry outbursts
- Sleeplessness

Do you recognize those things? Of course you do – you experience them. However, when you experience them, you realize that you need to take control of your environment, or escape it if you can, and give yourself time to settle. Who hasn't barricaded themselves in the bathroom of a club to get away from the noise and the people and the activity? A friend of mine once, when stressed about driving in the snow, said, "Turn the radio off, I can't see." This is normal. Odd, but normal. However, if diagnostic overshadowing occurs with an individual with a disability, these behaviours could result in a massive plan being developed and other, more obvious solutions may be lost.

Loneliness: One is the Loneliest Number ...

Let's take another example of how the 'neurotypical' person (as some are now referring to those without cognitive disabilities) reacts to ... say ... loneliness. Sometimes when speaking about the lives of people with disabilities, it begins to sound like disability and loneliness are two sides of the same coin. It isn't true of course, but sometimes it sounds like all typical people have full dance cards and a glittering social life and people with disabilities are all lonely wallflowers.. Um, no. People without disabilities and people with disabilities can experience loneliness. And guess what, they've done some research on what effects loneliness has on people. Let's take a look:

- Depression
- Suicide
- Cardiovascular disease and stroke
- Memory loss
- Learning becomes more difficult
- Decisions get harder to make and, often, poorer decisions are made
- Overconsumption of alcohol and drugs
- Loss of desire to exercise
- Loss of ability to sleep
- Drive to eat a higher fat diet

It's clear that living can hurt – anyone. It's also clear that we need to be alert to the living situations in which people find themselves. We need to be asking questions about the kinds of supports we offer, the kinds of opportunities we create and the support that we give. Looking at some of the kinds of experiences that PEOPLE find difficult, perhaps we need to ensure that if those we support are encountering similar stressors then the solution may not be a 'program,' but instead, an opportunity. More radically, perhaps sometimes people may need compassion more than programming.

Rejection: Gosh that Hurts!!

It was difficult to find a 'symptom' list for the experience of rejection, but there was an interesting study that causes one to pause and think about the experience we have as humans interacting with humans and about the experiences of many with intellectual disabilities. This study looked at brain patterns that form when people feel actual physical pain that was caused by a clear and visible event. Then the researcher looked at the brain patterns that were formed when people experience or remember experiencing rejection. What they found was that the brain patterns were precisely the same. They then looked at other emotions – anger, frustration, fear – and none of them did the same. Rejection as an experience is a painful one. It is no wonder that we speak of 'hurt feelings' and not wanting to 'hurt someone' and 'it breaks my heart.' There is actual PAIN.

This is important to consider when supporting people who might experience that pain on an ongoing basis, going into a restaurant and having the waitress speak to the staff not to you – is rejection. Going into a movie theatre and having a group of kids call you names – is rejection. Having been institutionalized – is rejection.

We all know how our behaviours are affected by pain. Do we ever stop to consider how people with disabilities might be experiencing actual pain and we expect them to simply 'ignore' it and carry on? Perhaps it's important to remember that pain needs healing not a good talking to.

Frustration: This Drives me Berserk!!

AAARRRRGGGGHHHH!!!!

Wanting to do something, but being prevented from doing it because of lack of skill or because of interference by others results in a huge emotional reaction. Frustration and anger can look and sound the same, but they are quite different. Frustration, as often as not, directs the emotion inwards – 'I'm stupid,' 'I'm clumsy,' 'I'm ugly,' 'I'm incompetent.' These are the kinds of things we say to ourselves when we plunge over the edge of our capabilities. It's not great knowing that what you want to be

able to do lies just outside your grasp. There isn't a single human being alive who doesn't deal with frustration arising from one cause or another. Guess that's why they did studies to demonstrate the effect of frustration on human emotions and human behaviour:

- Anger
- Burning out
- Giving up
- Loss of self-esteem
- Self-confidence
- Stress
- Depression

People think that frustration is a natural part of having a disability. To a limited extent they are right, there are barriers – both physical and attitudinal – that are cumbersome, bothersome and frustrating. However, as almost anyone with a physical disability can tell you, after becoming disabled (those born with a disability never have any other norm to compare it to), the frustrations are HUGE. But most of us – I am a wheelchair user and can attest to this – are taught 'how' to be disabled, 'how' to manage the frustrations that come with the territory. But many people with intellectual disabilities have never been taught that there are solutions to the frustrations they experience with their disability. Many have never been allowed to learn about or discuss freely their experience as disabled people and, when they do, they often hear "Oh, you are just like everyone else." This is much more hurtful than helpful. In fact, it's frustrating.

Bullying: I'm the King of the Castle and You're a Dirty...

We've even set taunting and name calling into children's rhymes. Bullying as an issue is coming into prominence due to a number of tragedies that have resulted from taunting, teasing and social torture. That bullying is a form of social violence is yet to be fully accepted as an idea. However, anyone who has ever been slapped by a word, or kicked by an insult knows that bullying is nothing if not violent. It seems that there is no arena where bullying hasn't made its presence known – the schoolyard, the workplace, places of worship, places of leisure – from coffee shops to shopping malls – bullying just seems to happen. As awareness rises, so does research. How do people respond to being bullied?

- Loss of desire to participate in activities
- Anxiety
- Low self esteem
- Negative self talk
- Headaches
- Stomach aches
- Ulcers
- Performance deterioration
- Trouble sleeping
- Nightmares
- Suicidal thoughts

We know, without question, that bullying can kill. It's interesting though that bullying and name calling of people with intellectual disabilities has yet to cause any kind of outcry. People who would never use sexist, racist or homophobic words will use *and defend* the use of the "R word." Many even dismiss the damage done because "they don't understand" ... um, if you read what self advocates say about being called names – they do. Perhaps, given the fact that research says that people with visible disabilities are most likely to be bullied and that people with disabilities report that they are bullied, often on an ongoing and daily basis – we should think about how that plays out and what behaviours may result. Teaching bullying prevention or strategies to deal with bullying might be wise. In fact, if someone is being bullied and their behaviour is a means of reporting that experience, isn't programming it away just a clinical way of saying "Shut up, we don't care?"

Happiness: It's All Good

It's important to end here on a more positive note. While it's true that there are emotional and behavioural signs and symptoms of the more stressful aspects of life, there are also benefits to a life full of happiness. While it was hard to find a study on this, there's a lot of opinion. Here's what some people say are the results that come from living happily:

- Increases ability to engage with the world
- Increases the willingness to try something new
- Increases the ability to ward off negative experiences
- Increases the ability to handle anger and frustration
- Increases the expressions of gratitude
- Increases the probably of success in new ventures
- Decreases irritability
- Decreases complaints
- Decreases negativity

It's clear that, to some degree, happiness is an antidote to a lot of what ails us. Therefore, if we make it our goal to increase happiness or at least the opportunities for happiness, some of the other things will fall away. We understand that a basic ethic in behavioural approaches is that we 'don't take something away without giving something back.' Maybe then we could make it our goal to take away the conditions that lead to a life of loneliness and depression and replace it with conditions that lead to a life of fulfillment and purpose. Just saying.

A Final Caution:

Have you heard of 'med students' disease?' This is where those studying to be doctors or nurses self-diagnose themselves with all sorts of conditions just by reading symptoms. The lists above are not for diagnosis, but for information – to make the point that human beings will be human and we need to remind ourselves of the essential humanity of people with disabilities ... that we can't give to disability what doesn't belong to disability. So don't read a list and think 'oh no ... I am suffering from ...' The goal is to reduce stress not cause it!

No, No, This One, It's the Final Caution:

Diagnostic Overshadowing is really just another form of prejudice. Prejudice clouds thinking, interrupts analysis and shrinks the number of questions being asked. When we are looking at the problem behaviours of people with disabilities we need to understand, and always remember that some human problems result in some human behaviours. Problems can cause behaviours, behaviours aren't always problems. Becoming alert and aware of the kinds of stressors and feelings that an individual is experiencing can lead to us all taking a more supportive stance with each other and with those we serve.

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