

# CULTURAL CURIOSITY AND DISABILITY

*When disability matters, and when it doesn't, within  
the larger picture of cultural influences*

BY GEMMA FRASER, RCC

"I don't have a disability all the time," stated David Hingsburger<sup>1</sup> at a conference I attended many years ago. It was one of those profound moments in my counselling career. I looked at this man in a wheelchair, and I realized I had been missing something.

In my attempts to be nurturing and mindful of my clients' disabilities, I had stopped checking my own fundamental assumptions about disability. I had assumed that you either have one or you don't and that its impact is lasting, static, and consistent. I had been "disability blind" in a similar way to people who are "colour blind" when it comes to race.


Hingsburger explained that his disability "matters" when his ability to function is compromised, like when he

is unable to access a building or bathroom. At other times, his disability is not an issue, like when he's enjoying good conversation with friends.

My curiosity about what it means to be an individual with a disability was piqued. When does it matter? And when is the fact of disability not really relevant? How is disability defined by different cultures? And who defines disability anyway? Most important, I began to explore what this meant for me as a counsellor working with individuals and families with disabilities.

## **KNOWING THE STORIES**

It is easy to assume someone with a disability is in counselling because of an issue arising directly from the

A person is shown in profile, seated in a wheelchair. The scene is backlit by a bright sun, creating a strong silhouette effect. The person is wearing a light-colored, short-sleeved shirt. The wheelchair's frame and a large rear wheel are visible in the foreground. The background shows a bright, hazy sky with a distant horizon line, suggesting an outdoor setting like a beach or park at sunset or sunrise.

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disability. But this presupposition may affect how open we are to hearing our clients.

David Pitonyak,<sup>2</sup> whilst not speaking specifically about counselling, points out that many of the failures in support provided to people with disabilities result from not truly knowing the individuals we are supporting. “We don’t know people’s stories and we don’t even notice that we don’t know them.”

UNLESS WE TRY TO KNOW SOMEONE WITH A DISABILITY THOROUGHLY — KNOW THEIR STORY, KNOW THEIR FAMILY’S NARRATIVE, AND UNDERSTAND THE CULTURAL STORY SURROUNDING THEIR LIFE AND DISABILITY — **WE MAY BE MISSING CRUCIAL INFORMATION FOR THE THERAPEUTIC PROCESS.**

As counsellors, it’s easy to assume we are more attuned to hearing clients’ “stories” than those in other support roles. However, I suggest that unless we try to know someone with a disability thoroughly — know their story, know their family’s narrative, and understand the cultural story surrounding their life and disability — we may be missing crucial information for the therapeutic process.

In reality, disability is a social construct,<sup>3</sup> defined not just by the DSM-V,<sup>4</sup> the World Health Organization,<sup>5</sup> and other agencies that “define” different types of disabilities, but equally by the narratives the person with a disability, their family, and their community have built around it. Each of these is embedded in a cultural background unique to the individual. As McGoldrick, Giordano, and Garcia-Peto point out:

“Cultural background refers to our ethnicity, but it is also profoundly influenced by social class, religion, migration, geography, gender oppression, racism, sexual orientation, and family dynamics. All these factors impact people’s social location: access to resources, inclusion in dominant definitions or ‘belonging,’ and the extent to which they will be privileged or oppressed within the larger society.”<sup>6</sup>

This cultural backdrop influences how a person with a disability is viewed by family members and the greater community, as well as assumptions about the “why” of disability and the “how we deal with disability.”

#### **RESPECTFULLY CURIOUS**

In many ways, counselling people with disabilities does not differ radically from any other counselling situation. Establishing a warm, respectful relationship, clarifying and interpreting what is shared, and instilling hope are all basic tenets of any counselling session. In my experience, the issue that brings a person with a disability into therapy has the same underlying current as any other: anxiety, depression, loneliness, hopelessness, a desire to change but an uncertainty about how to achieve change.

However, without understanding the cultural context of their disability, we may miss opportunities to understand their unique experiences. It can be helpful to explore what the disability means to the individual and their family and how they view their place in the community. Each of these narratives will have been informed by the individual’s unique cultural heritage<sup>7</sup> and will affect their willingness and openness to seek and accept support, their sense of isolation



and marginalization, and their feelings of adequacy and belonging.

As an example, I was struggling to understand why a client with a disability was so negative and critical of himself every time we met, despite the fact that he was doing exceptionally well in school and at work and was hoping for a promotion. I kept trying to explore this with him, anticipating that he would begin to explain how difficult his struggles were due to his disability. I was not getting very far. I then began to ask him more about his cultural heritage and what it means in his country of origin to do well at school and strive to do well at work. He explained that for males from his country, self-criticism is an important step toward self-improvement; particularly for managers (the work role he was aspiring to), it is seen to be a necessary and sought-after characteristic. It dawned on me that what I had been hearing as very worrisome negative and self-critical

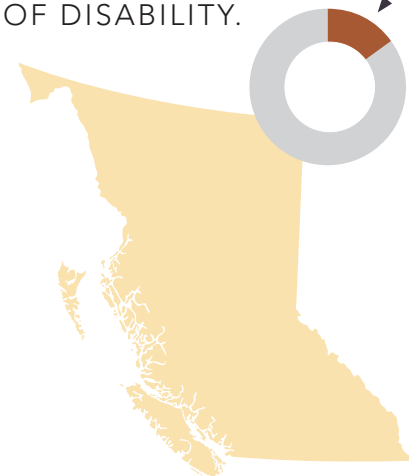
messages had, in fact, been his attempt to show me an area of strength. He was self-critiquing, rather than self-criticizing — a subtle but important difference. If the critiquing is a valued characteristic according to his culture, my work as his counsellor is not to temper it, but rather to help him move beyond it and into the work of implementing the changes he sees as necessary for work advancement. His disability did not really matter in this instance. His critiquing wasn't really the issue either; his being stuck there was.

### **COUNSELLOR BIASES AND ASSUMPTIONS**

Olga Silverstein eloquently reminds us that the “techniques [you use] can only take you so far. The therapist’s life experiences and point of view are always crucial to helping people change.”<sup>8</sup>

Just as we continually examine our beliefs and understandings of culture,

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gender issues, and personal triggers, we also need to examine our own prejudices and thoughts regarding disability. From this place, we are better able to provide counselling less burdened by preconceived ideas about disability, and we allow room for our clients to be more inventive and creative as they deal with the issues they are experiencing.

The challenge for therapists is to examine and set aside our assumptions that presenting issues are fundamentally a result of the disability. Instead, we need to remain curious about the larger picture of how family and community

messaging plays a part in the presenting issue and also remain aware of how our own cultural biases are influencing our work with a client.

**IS THE PROBLEM ACTUALLY THE PROBLEM?**

Often, people with developmental disabilities end up in therapy at the suggestion of family or support staff who deem certain behaviours “problematic.” During any therapeutic session with a person with a disability, it is important to establish if the disability is “causing” the problem or if, instead, a pattern of communication<sup>9</sup> has arisen due to a specific narrative around disability derived from the family, community, and cultural background. It helps us to determine if there is another factor instigating the problematic behaviour.

It is easy to fall into the trap of assuming it is a case of identifying the problem and then applying behavioural changes to reduce the occurrence of the problematic behaviour. Indeed, it is common practice to implement support plans aimed at mitigating problematic behaviours without first examining the reason the issue exists. In so doing, we may miss the point altogether. As David Pitonyak suggests, “Difficult behaviours are often an individual’s only way of creating engagement.”<sup>10</sup> We might get change, but whether it will be lasting and sustainable is doubtful, and we will have done a disservice to the client if they were trying to engage in the only way they knew how.

As therapists, we cannot be experts about every issue that comes our way. Instead, we need to be respectfully curious about the context surrounding any issue in order to fully understand it.<sup>11</sup>

When a family member has a disability, the subtle and overt messaging regarding disability arising from family values, community, and cultural ideals will play out as the family makes sense of how disability fits within their narrative and place in community. It can be helpful to explore long-held beliefs about disability and questions surrounding the “why” which may have never been discussed and, yet, may profoundly affect the way the family operates and whether the individual feels connected or marginalized. Do they believe disability is the result of bad luck, or faulty genes or vaccines, or drugs or alcohol?<sup>12</sup> Are there feelings of guilt and shame and then shame for feeling ashamed? What beliefs have been instilled regarding the capacity of people with disabilities to contribute meaningfully to

the family and society? How is reaching out for and accepting support viewed? The answers will be influenced by culture, gender, race, and age and will affect the narrative and resultant behaviours of the individual.<sup>13</sup>

### THE REAL DISABILITY

The number of people being diagnosed with disabilities is growing. In 2012, Stats Canada estimated that almost 15 per cent of B.C. residents have some form of disability.<sup>14</sup> Some will seek therapy for mental health issues that may be a direct result of the disability. For others, the disability won’t be the issue at all, but it will always be in the backdrop. We need to ensure we are respectfully curious about what it means for each individual to have a disability. Otherwise, we risk inadvertently contributing to feelings of isolation, loneliness, and being misunderstood.

As Beth Snow and others have said, “Loneliness is the only real disability.”<sup>15</sup> When people come to counselling, whether they have a disability or not, they are looking to be truly heard. They want to tell their story and explore how it makes them feel. Cultural heritage informs these stories in both subtle and important ways, and our curiosity about this aspect of someone’s life can help us understand more fully their unique experience. We are best able to do this when we check our assumptions about disability at the door and remain, instead, respectfully curious. ■

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### ENDNOTES

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