I’VE NEVER HEARD OF THAT DISABILITY: WHAT DO I DO?

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When one is making efforts to enhance inclusion in your congregation, it’s not uncommon to start to notice a lot of people with disabilities around you. They’ve always been there, but, as you become sensitive to inclusion barriers, it’s quite common to notice different types of disabilities.


And yet, let’s examine that assumption, because I’m going to offer that not only do you not need to know, frankly, you will be a better more welcoming community leader, and ultimately a better friend, if you don’t try.

Should the day come in your life when you are diagnosed with one of these conditions, you will need to learn all about it, at least as it pertains to you. This will help you to seek the best medical treatment, and it will help your doctors to provide the best care.

To welcome someone into your community, however, for whom the interaction of a medical condition with our communities as they currently exist creates a barrier to participation, you only need to know what that barrier is and how to overcome it. If a person can’t walk and needs a ramp, it doesn’t really matter whether that cause is spina bifida, cerebral palsy, or muscular dystrophy, for instance.

What’s more, this is definitely a situation where a little knowledge, improperly used, can have a very unexpected result. First of all, while it’s always appropriate to respectfully ask people about their barriers and try to help them overcome them, it’s really never appropriate outside of a medical context to ask people for a diagnosis that they did not volunteer.

Secondly, even for medical professionals, these diagnoses often provide no information on the barriers that a particular person faces. I have cerebral palsy, and, in my case, the primary manifestation means that I can’t walk, my hands don’t work very well, and you might notice some breath control issues. It turns out, however, that cerebral palsy is a blanket medical term for any damage to the motor control center of the brain before age 2. A person with cerebral palsy maybe anywhere on a spectrum from completely without speech and barely any voluntary control over their movements to someone with such slight coordination issues that you would not know that
they had a disability at all without running a brain scan or an orthopedic test. Nor is cerebral palsy unusual in this regard. Every medical condition presents differently for every person, and a short description is more likely to mischaracterize an individual that you actually deal with than provide useful information.

This naturally leads to the third problem, which is, should you encounter someone with a particular diagnosis that they choose to share with you, and should you have learned some basic things about that diagnosis, you run the terrible risk of applying what you read to the person, and you miss the real goal of welcoming, which is listening to the barriers that that person faces in his or her own life, and helping them to overcome them and participate. You don’t want to have a checklist in your head of expected symptoms or barriers when you meet a person. You just want to listen.

In short, it’s only natural to want more information about particular disabilities, but unless you have such a disability or are professionally researching or treating such disability, resist that in favor of learning about the person.