

PHI: *I usually call myself a 'polio-survivor.' I've heard some people say 'polios' and others say 'living with the after effects of polio.' Some say 'I'm handicapped' and others say 'I'm disabled.' Are these all acceptable, or am I accidentally insulting someone if I use the wrong language?*

Response from Rhoda Olkin, PhD:

Such a great question because words convey concepts. They also may convey a political stance or a value judgment. For example, think of these words: girls, ladies, broads, females, women—these all mean essentially the same thing but would be received very differently. Words related to disabilities, including polio, likewise carry meanings beyond the words themselves.

Let's go through some language. First up is 'polios.' I personally dislike this term as it reduces us to a single factor and feels not that much different than saying 'cripples' (a once regularly-used term that is now considered highly derogatory). 'Polio survivors' is better as it conveys resilience and life after polio, but it still is a single demographic devoid of context. 'A person living with the after-effects of polio' is a wordier version of polio survivor. 'A person who had polio' starts to suggest that the person has other things about them besides polio. I don't think any of these are wrong and within polio circles would be well received.

Another language issue is whether we 'polio survivors' consider ourselves part of a larger group of people with other types of disabilities. For about 20 years, 'people first' language was encouraged: 'a person with polio' or 'a person with a disability.' In this language, the person was central, and the polio or disability was one thing the person 'had' (not 'is'). Recently within the disability community, there has been a move towards 'identity first' language: a disabled person. This connotes disability as an essential part of identity, disability pride, and affiliation with the disability community.

What are the differences among these terms: handicap, impairment and

disability? The World Health Organization distinguishes these terms as follows:

Impairment: This term is used by professionals to identify some disruption at the system level of an organ in the body, like the brain or the left leg, that leads to loss of use or some variation from a norm. Impairments are not defects and they can be psychological, physiological or anatomical; some are permanent, others are temporary. Impairments can lead to disruptions in thinking, emotion or behavior.

Handicap: A handicap is an obstacle that affects people because, once present in their environment, it blocks them from completing some role. Thus, a disabled person can be *handicapped*—that is, disadvantaged—by a missing ramp, but the handicap does not reside within the person.

Disability: "Disability results from the interaction between individuals with a health condition such as cerebral palsy, down syndrome and depression as well as personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support." As such, disability is not a feature of the person but of the interaction of the person and the contextual variables (e.g., attitudes, built environments, economic policies).

Whichever language you use, it needs to feel right to you and nobody else but you. The way in which polio played a part in your life may lead you to feel more comfortable with one phrase over another, and that is okay. (Rhoda Olkin describes herself as a polio survivor, a disabled person and a disability rights activist.)



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PHI: *I just recently moved and joined the post-polio support group in my area. Because of the pandemic, they aren't holding any in-person meetings. The group has a private Facebook page and gets together on Zoom each month. I've only been on a few calls, but I'm finding it hard to fit in. I'm not overly shy, but I feel a bit like an outsider and am reluctant to speak up. Any advice?*

Response from Stephanie T. Machell, PsyD:

It might be Zoom. While it may be easy for you to enter a physical room full of strangers and quickly feel comfortable speaking with them, entering a Zoom room full of unfamiliar people is a different experience. Information you would automatically gather and rely on to guide your interactions may be more limited and/or difficult to read.

Interactions will be limited as well. There may be little or no informal chatting before the meeting starts, and any that does will include all present, with no opportunities to speak one-on-one or in smaller groups. It can be challenging to know when it's your turn to speak or whether others are paying attention when you do. And no matter how hard you try, it's difficult not to watch yourself, which can increase your self-consciousness.

Or it might be the group. Groups vary in how welcoming they are to newcomers, especially if the members have been together for a long time and are more interested in catching up with each other than getting to know a newbie. Ongoing discussions about the experiences of longtime members may be difficult for a newcomer to join in meaningful ways. Or the group may have done a good job of welcoming new members in person but failed to consider how to do this on Zoom.

When you attend the next meeting, take the pressure off yourself about participating. Instead, observe the group and its interactions. See how much you can discern about each member and about group norms around participation. In the absence of eye contact, can you identify

signs that members are listening to each other? What cues do they use to know it's their turn to speak?

As you observe, think about how you feel about the group as well as how the group makes you feel. Are the issues they're addressing relevant to you? Is there too much (or not enough?) negativity, either about living with PPS or towards other members? Do certain members dominate or is there an equitable division of time? Are they welcoming to you as a newcomer and respectful of each other?

Getting to know a few people will help you feel more like part of the group.

Consider whether there are one or more members you'd like to get to know better and use Zoom's messaging function to send them a private message asking if you could speak with them later (make sure you are sending only to them and not to the group!) or reach out via a private message on Facebook or by email. Getting to know a few people will help you feel more like a part of the group.

After observing the group, you may decide it's not right for you. Not all groups are a good fit for everyone. Even if you do decide to stay with the new group, if your former group meets on Zoom, why not continue to attend their meetings and benefit from the extra support and camaraderie? ■

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