

Who Is a “Caregiver”?

Revolutionary Common Sense by Kathie Snow, www.disabilityisnatural.com

Internet. Weapons of mass destruction. Digital. New words and new meanings for existing words become part of our everyday vocabulary. CAREGIVER is one of those words. I believe this word is misused and, in the process, it can cause negative and unintended consequences. I think it’s an “Ugh!” word!

Stories about CAREGIVERS abound in magazines, newspapers, and TV news, and there are CAREGIVER associations! But even with all this attention, there doesn’t seem to be a universally-accepted definition of the word. What do we mean when we use this term about ourselves or someone else?

I’ve seen or heard the following described as CAREGIVERS: parents and family members of persons with disabilities, adult children who help an “aging” parent, child care providers and babysitters, staff members at nursing homes and congregate living environments, and others who do something to or for another person.

Wow! This list covers a lot of territory. Like other labels, the CAREGIVER descriptor lumps many people into one category, even though they may have little or nothing in common with one another. Many people may be *described* as CAREGIVERS, but is that really what they are?

If a person is *paid* to provide care or assistance, CAREGIVER seems to be an accurate term. But a parent who takes care of a child with a disability is a *mom or dad!* That’s what parents do!

Other family members who provide assistance and help to a person are more accurately called *brother, sister, aunt, uncle, grandparent*, or whatever!

And an adult who helps take care of an “aging” parent is a *son or daughter!*

Not too many years ago, people who were related to one another and who took care of each other were simply called “family.” What’s changed?

First, we love to “categorize,” “medicalize,” or “institutionalize” just about everything! So we’ve turned the naturally-occurring help provided by family members into the socially-constructed CAREGIVER role.

Second, our extended families may not be as geographically close as they once were. In most corners of modern societies, seldom do we see three generations of family members under the same roof. But for most of recorded history—and in some societies *today*—grandparents, parents, children, and perhaps other relatives shared life and supported one another under one roof. We say that Western or “modern” nations have “progressed” beyond this practice, which some

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consider “primitive.” (And when we discarded this practice, we lost a lot.) But, in multigenerational homes, would *anyone* be called a CAREGIVER? I think not. Family members simply take care of one another because *that’s what families do!*

Third, we’ve been influenced by portrayals created by the media, politicians, CAREGIVER associations, and others. In general, a CAREGIVER is portrayed as someone who is “overwhelmed” by the “burden” of taking care of another, as evidenced by “CAREGIVER burn-out,” “caring for the CAREGIVER,” and similar stories. We’re led to believe that being a CAREGIVER is one of the world’s most difficult

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jobs! And some people seem to relish turning the CAREGIVER status into a “victim” role.

Yes, caring for a family member may involve a lot of work. *That’s life!* Our parents raised *us* through good times and bad, with fewer modern conveniences, less money, and so forth. But they did it—even if it was hard—because it was the *right thing to do*. And what about our parents’ parents who had to survive the Great Depression, World War II, and more?

I’m not implying that everyone can “do it all.” *We should* ask others for help. But I hope we’re not tempted to adopt the martyr-like role implied in today’s portrayal of CAREGIVER just because helping someone we love may be difficult at times!

I’m troubled by all this. Again, if someone is *paid* for services, CAREGIVER seems to be an accurate term. But what unintended consequences may occur if a mother decides to see herself as CAREGIVER for her child with a disability, or if an adult calls herself a CAREGIVER because she’s helping her 80-something mother? In these situations, we’re essentially exchanging our original role (mother, father, son, daughter, brother, sister, aunt, uncle, cousin, friend, or whatever) for a detached, somewhat “professional” position. In turn, this can create an invisible barrier between ourselves and a loved one. Shall we risk tampering with this precious relationship?

Furthermore, once we wear the CAREGIVER cloak with a family member, we may assume certain responsibilities that cause further disintegration of the familial tie. For example, if I assumed the CAREGIVER role for my 82-year-old father, I might feel this entitles me to make decisions about his

life, *even though he could make those decisions for himself*. The CAREGIVER role can quickly escalate into authoritarian power and control.

What would *you* want if *you* were the person needing assistance? Picture yourself as a child with a disability. Do you want a *mother*, or a parent who considers herself your CAREGIVER? Now jump forward and visualize yourself as an 82-year-old. Do you want loving and respectful assistance from your *son*, or from your adult child who calls himself your CAREGIVER?

Furthermore, within some government-funded programs in some states, parents or grandparents of children with disabilities are allowed to assume an “official” CAREGIVER role and be paid for their “services”—help they would need to provide anyway, just because they’re the parents! What effect does this practice have on the family relationship?

Words mean something. Words mean a lot. CAREGIVER, when used inappropriately, can lead to unintended harmful consequences. And to cavalierly wave off the meaning of words is to ignore the power of words in shaping our attitudes and actions.

When my son was younger and I was vying for the imaginary “Therapy Mom of the Year” award (before I knew better), Benjamin routinely and adamantly announced, “Mommy, you’re not the therapist. You’re my mom.” I won’t make the same mistake twice. Benjamin needs lots of assistance, but he’ll never need to say, “Mom, you’re not the CAREGIVER. You’re my mom.” And I’m instructing my children that when my husband and I are older and we need help, we want them to always be our daughter and son, not our CAREGIVERS. We want our family to remain a real family.

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