

Foreword

What do we Call “Them”?

The problem occurs every time I write a book or an article. The editor kindly informs me that my wording is awkward and needs to be changed. I’m told that: *it doesn’t offer a convenient format*. The offending verbiage is always the same – *a person, who also experiences disability following brain injury*.

It’s too long, I am told, or It’s too awkward, doesn’t fit convention, takes up too much space, is inconvenient, - and ultimately, takes too much time and patience to understand.

So, I ask, *what do you call them?*

Brain injured, the brain injured, disabled, impaired ... the list goes on.

I fight the urge to respond in kind, noting that the speaker is too tall or short, fat or thin, old or young, inflexible, or awkward in their own way because none of this matters. Sometimes I even suggest that I now call this person *WIMP*. It’s short for Word Improvement Manuscript Professional. It contains fewer letters and syllables than *ED-I-TOR*.

However, my primary relationship with this person is as an editor; someone who helps me better convey my thoughts to others. And the editor puts up with me, believing that I have something of value to say; even if what I have written is presented awkwardly; never mind my insolent nature. We transcend this specific point and relate more fully to whom each of us is as an individual and the reciprocal benefit of our collaboration.

So what do we call *them*?

We don’t.

There aren’t any *them*’s, but Sally and Wesley and Saul and Dana. There are mothers, fathers, husbands, wives, partners, sons, daughters, aunts, uncles, cousins, friends and lovers. There are those who love, those who hate, those who are too lost to feel and those who are ambivalent. Somebody may be a student, a teacher, or simply deciding that it is time to decide. There are people who cook, sing, advise,

treat, construct, weld, con others, or don’t even have to explain their actions. There are people living in prison, in mansions, on the street and next door. Some people do these things better or worse than others. Some people simply don’t care.

Each *them* is unique, as an individual and as part of other people’s support circles; or at least *them* should be. But following brain injury, too many individuals get plucked from their circles; sometimes due to emergencies, a need for intensive treatment, or equally necessary and timely reasons. When the person doesn’t get reconnected he or she becomes *them*. It’s rarely a conspiracy, but often a custom.

We diagnose *them*, evaluate *them*, treat *them* and research *them*. Dissected and fragmented, it is too easy to look at the pieces but not the whole; perhaps a preferred and necessary perspective when excising a hematoma, fixing a broken limb, or other singularly urgent issues. But is it ever any wonder why people don’t “work” the same when they are not “put back together again?”

This may not seem possible for many people after a brain injury. Too many things have changed and “complete” recovery is often illusive. But, it’s probably time to get off the recovery bandwagon, anyways, at least as it relates to the cadence of each person’s life. People never go backwards and recover, they move forward and grow, albeit in sometimes unintended directions. We recover from colds, broken hearts and other encapsulated events. However, for many people, residual effects of the brain injury and associated events live on. Time marches on and so does life changed by brain injury; rather than life “after” brain injury.

As a matter of being, each of us refocuses, redefines and reconstitutes our lives according to new challenges or opportunities. This process becomes more difficult and delicate, however, when one exists in or is ascribed to a dependent role. But this should not prevent the pieces of life’s puzzle from being reorga-

*Life is the art of drawing without
an eraser
John W. Gardner*

nized into a different picture, as long as the forest is recognized along with the individual trees.

So, it is not “just” about the brain injury. It’s about the person, others’ lives, hopes, resources and so many other factors that define a person’s full circle of life. If you could restore a person’s brain without restoring their life’s canvas he or she would not be who they were. And, restoring a person’s life without restoring their brain would be equally empty. Neither approach portends a capable future.

Of course, life is not a simple “either/or” dichotomy. Life is messy. One brain may be injured in a car crash or assault; as a result, many lives are changed in both obvious and subtle ways. Focusing only on the obvious is akin to buying a car because it has a nice paint job, without also checking the tires, battery, steering, engine, suspension and transmission. You might get lucky, but you probably won’t go very far. Still, you can always kick another tire and buy another car. People are not cars and not so lucky.

Too many individuals get blamed or shamed, even when they are not at the wheel – because they are expected to be. Yet, at the same time, the person is often prevented from being there. Brain injury and accompanying disability rarely absolve an individual from the consequences of their personal responsibilities. Yet, the presumption of incapacity too often prevents a person with the opportunity to assume personal control of these same responsibilities. *He has a brain injury ... It would be too confusing ... It will take too long ... she might over-react ...* and on and on and on. Is there any question why people get angry, depressed, despondent or go nuts?

When a person is objectified on the basis of impairment, his abilities, resources, and potential often go unrecognized and get lost. Acknowledging each person within the context of her complete life, heritage and support circles opens a plethora of opportunities and places personal limitations in more accurate perspective. Hence, one is not either *brain injured* or *not*, but obviously has a range of abilities and challenges, some of which may have been affected by direct or indirect involvement in a brain injury. Behavior changes for many people, and not just the person who directly experienced the brain injury.

This approach also provides a more even playing field regarding personal rights and responsibilities. It is easy to get confused regarding what rights belong to “the disabled.” Perhaps this is the wrong question. Instead we might more appropriately recognize the rights and responsibilities of the total person, acknowledging accommodations that society or the law may have established for unique personal attributes/challenges.

Rights without resources rarely offer realistic options or opportunities. We see it too often in “community-based housing” that may be little more than institutionalized living in smaller community-based packages; in inadequate transportation options that bureaucratize rather than facilitate realistic community access; in representation of presumed personal interests that don’t emanate from the *President and CEO of ME!* It is too easy to get lost in the process of delivering services and forget that the original intent was to support relevant and coherent lives. The lifestyles that were supposed to be enhanced by such processes can get twisted into a strange cacophony of adapting to possibly well-intentioned but misconstrued service delivery systems.

Regarding the full person reduces such effects because it returns focus to that person’s complete life. It is not about finding a handicapped transportation service, but a way to get to a friend’s house, to work or to the store in time to cook dinner for one’s family. It’s not about disabled housing, but finding a place to live that promotes one’s independence and diverse activities. It’s not about brain injury support group night out at the bowling alley, but bowling because you like to. Just like anybody else, these choices are made within the realm of options, resources and responsibilities. Miss the bus and you won’t get where you are going. Try again, or try another way, within the total context of the person’s life and circles of support. *Separate but equal* ultimately has never worked for any designated group, or for the betterment of our society. We are all in this together.

So, if you think that anything but ascribed roles separates *a person, who also experiences disability following brain injury* from a person who hasn’t, you are sorely mistaken.

***Stop treating the brain injured
Start collaborating with complete individuals***