Beyond the Box

Kerry Wiley, M.S.W.

Abstract

Our current health systems, while gradually changing, have taught numerous professionals to think in boxes, to categorize by labels and diagnosis, rather than look at the sum of the whole. This article explores the relationship between people with disabilities and professionals, from the perspective of the author, who has a lifelong disability.

Keywords: professionalism, social model of disability, strengths approach,

Kerry Wiley, M.S.W., has a long history of developing advocacy and self-advocacy endeavors. She has worked in the disability field in research and program development for 15 years.

Please send correspondence to kwiley01@nycap.rr.com.

This copyrighted article is reproduced from the “Endless CapABILITIES Blog”, sponsored by The National Center on Health, Physical Activity and Disability (www.nchpad.org). NCHPAD is part of the UAB/Lakeshore Research Collaborative and supported by Grant/Cooperative Agreement Number U59DD000906 from the Centers for Disease Control and Prevention (CDC). It may be freely distributed in its entirety as long as it includes this notice but cannot be edited, modified, or otherwise altered without the expressed written permission of NCHPAD. Contact NCHPAD at 1-800-900-8086 for additional details. http://blog.ncpad.org/2012/03/19/beyond-the-box-part-i/#more
Beyond the Box

Our current health systems, while gradually changing, have taught numerous professionals in my opinion, to think in boxes, to categorize by labels and diagnosis rather than look at the sum of the whole.

As a child, I remember hearing very technical and medical terms like “Spastic Diplegia” (the type of Cerebral Palsy that generally affects both legs) or “Spasticity” (involuntary movement which can include stiffening of muscles).

I knew that I was the subject of discussion but did not understand what was being said. All I knew was people were touching me, prodding me, tapping me with instruments to test reflexes and other functions and the results ended up being written in folders with my name on it. I felt like a science experiment.

Over the years, I have encountered various types of work styles with professionals including:

- **Professional 1: The Explorer/Scientist/Mechanic**
  “Kerry’s Hamstrings don’t work… Her hamstrings and gastrocnemius muscles are tight. Kerry is the experiment/project in the room – What can “we” do to get her to be like the image of function we know? What can we do to “correct” the anomaly…?”

- **Professional 2: The Realist**
  “What is, is… She has x and y capability… that is all there is. Maintaining function is the ‘best’ that can be gained.”

- **Professional 3: The Drill Sergeant**
  “We have a set program for Kerry; we are going to push her. She is going to achieve the defined goal.”

- **Professional 4: The Maverick**
  The Maverick is the out-of-the-box thinker that recognizes the need for a different lens and has the willingness and ability to try different approaches to accomplish what needs to be accomplished (see photo).
All of these work styles illustrate a varying level of expertise, comfort level, and awareness. In each case, it creates a role where I must be a student and a teacher to level the playing field. I often sat on the treatment mat or table watching while discussions were occurring about me, feeling isolated, very small, and compartmentalized.

I remember feelings of wanting to escape or run away. It did not matter how big the room was. I was not restricted but I felt boxed in. I would become quite distressed because I did not know how to say at the time that I was not an object, a subject in a box or experiment to be studied. I was there. I was sitting in the room and had a very clear perception of events.

Those feelings of vulnerability were a driving force that caused me to become a skilled student about all aspects of my disability. I learned everything that I could about Spastic Cerebral Palsy. I had to learn to be constructively vocal and learn to ask questions in the right way. I had to learn the same terms, learn about the therapies, and protocols just like the professionals did to establish productive working relationships with them. I learned that I was choreographing an intensive and dynamic relationship with the professionals, and nothing about it was standard or routine.

A good teacher sets high expectations for achievement; they provide the vision, knowledge, and a plan to move ahead. When I work with a new professional, I am looking for certain qualities. Are they a Maverick - the out-of-the box thinker that recognizes the need for a different lens when dealing with a disability? Do they have a willingness and a level of skill to try different approaches? Do they have patience, confidence, and an ability to provide direction?

In turn, I try to display the qualities of a good student—that I am focused, set goals, am confident, and that I have a positive attitude and am open to direction. A good student prepares, is not afraid to ask questions, is respectful, and is always on time. I switch between a teacher and a student role. When I work with professionals, I have to become knowledgeable about specific therapeutic techniques and what should be occurring with those prescribed methods. I have to learn to keep pace with each professional based on their training, practice, and protocols. Initially the new professional and I are not on equal footing.

I often have to challenge academic teaching, theories, and what the person has read or heard about Cerebral Palsy. There can be a tug-of-war between what the textbook says compared to what professional sees when they work with me. I often have to teach, encourage, and give confidence to the professional to trust me and what I share about the “in the skin” experience with my disability.

I have to show the professional that I am the master of my own body and clearly know what my strengths and weaknesses are. I have had to learn how to fine-tune how I engage with professionals. This includes how I relay and share information. I have learned to use different vocabulary and communication styles; sometimes my methods are short and to the point or are very detailed. I had to learn when to be forceful and when to be calm about my wishes and when to clearly steer my treatment direction.
I have had to become a skilled facilitator. Becoming an effective facilitator is a mix of several skills including listening to information that is conveyed by the professional, listening to instruction and repeating the information back to be clear, asking questions, and being able to put into words what happens when a particular technique is tried.

As we train new professionals coming into the recreation, health and fitness fields, we need to instill more Maverick-type qualities - seeing the person absent the diagnosis and moving beyond the box.

Video “Boxing Lesson” provides a glimpse into a work session with Kerry and a maverick professional, James House, III. Kerry and James were using boxing to work on stance and balance.

You can read more blog entries by Kerry Wiley on the National Center for Physical Activity and Disability blog site at http://blog.ncpad.org/.

The “People Factor”

I came across an old photograph from 1979. In the picture, I am lying across a therapy ball that is about four times my size. My dad, Terry Wiley, is swaying me back and forth on the ball, performing my nightly stretching exercises. The exercises were designed to keep my leg muscles loose and pliable.

When I look at that picture, I see a happy kid not yet overwhelmed by notions of disparity, difference, or concepts of disability. In that picture the concepts of etiology (causes of a condition), diagnosis, and disease were foreign to me. I was just “exercising” and hanging out with my dad.

While all of these medical--oriented notions like etiology have their place, I am frequently reminded of the incongruence of these concepts and the idea that people come first, especially in program design and implementation. A recent session with my trainer brought the “people factor” notably back into focus for me.

My trainer asked one of his colleagues to work with their clients in another location of the fitness center. The room that we would be working in was warmer. My trainer knew my muscles would be more pliable and would respond better in the warmer temperature. He also knew that I would be less distracted from the music playing on the main floor coupled with the bustle of other the patrons. The request to have their colleague move locations gave me the space, quiet, and poise to work through the new nuances of my routine.

My trainer once said “People are my business.” What does that mean in practice? My trainer is aware of factors which impact my performance outside my diagnosis and the etiology of my disability. He makes specific efforts to remove elements such as cold, restricted space, and distraction which might impact and complicate my participation, movement, or access. The introduction of more space and quiet space assists me if I respond unexpectedly to a new exercise method (e.g., have a limb go spastic, rigid, or spasm). The extra space can also remove feelings of self-consciousness and the sense of spectacle that can result if a lot of people are around and something goes awry while implementing an exercise.

The “people factor” as described here infuses consideration, dignity, and respect of an individual into the formation and implementation of a health, fitness, or exercise plan. In our existing recreation, health and disability fields, people, not diagnosis, in my view, should be our first and most important business.