

QUALITY OF LIFE

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

QUALITY OF LIFE—it's discussed in medical settings, debated by scientists and non-scientists, and litigated in courtrooms. And for many children and adults with disabilities, a lifetime of treatments, interventions, and services are devoted to improving a person's quality of life. But who defines quality of life, and is there a definition embraced by all?

The dominant power of the medical community has, it seems, determined a "good" quality of life is related to functional skills: breathing, walking, talking, hearing, seeing, behaving, eating, eliminating waste, and so forth, in the "normal" fashion. (And the dictates of the medical community heavily influence human services, education, and the general public, and then become conventional wisdom.) So if one doesn't have "normal" functional skills, a "poor" quality of life is assumed. Thankfully, people with disabilities routinely demonstrate that the *absence of functional skills* has little or nothing to do with quality of life!

For decades before his untimely death in 1995, Ed Roberts, the father of the Independent Living Movement, taught thousands the real meaning of quality of life. After contracting polio as a young teenager, Ed could move only two fingers on his left hand—he couldn't even breathe on his own. So he needed a power wheelchair (which he controlled with those two fingers), a portable ventilator attached to his chair, and assistance to do everything except speak! If Ed was seated next to you at dinner, he might invite you to pull the breathing tube out of his mouth, pop a bite of food in, and then put the life-giving breathing tube back in.

According to conventional wisdom, Ed's quality of life would be considered "poor." But was it? He traveled the world to share the Independent Living philosophy, won a MacArthur "genius" award, and did so much more! He lived a fuller, richer, busier

life than many people who can walk, breathe, eat, wipe their own bottoms, and perform other "normal" functional activities. Ed personally demonstrated and professionally educated others that *being in control of your own destiny* represents the real meaning of quality of life. He helped others learn that the only person qualified to judge quality of life is the *person living that life*. Only Ed—no others—could measure *his* quality of life!

Ed was in charge—to decide the who, what, where, when, and how of his life—thanks to assistive technology, supports, and accommodations. With these "tools," he had the power and freedom to make his own choices. Sadly, many people do not have the tools that would enable them to be in control of their lives. Many don't have a communication device, card system, the ability to sign, or other method to effectively share their wants, needs, or feelings. Similarly, some people are denied the mobility devices they need. And still others *attempt* to exert control over their lives, but are routinely ignored or even punished for their efforts!

**The strongest
principle of growth
lies in human choice.**

George Eliot

Consider this other lesson about quality of life: on your deathbed, as you're reviewing your life for the last time, will you think, "I'm so glad I learned how to walk [or talk or read at grade level or perform any other functional skill]?" Or will you be thinking, "I'm so grateful for my wonderful family and friends and all the great times we spent together..." These thoughts—about *relationships and experiences*—reflect the measuring stick of *real* quality of life!

Sandra and Chuck, the parents of 10-year-old Charlie, who has Down syndrome, were told to move to a lower altitude. This, the physician said, would improve their son's quality of life: *perhaps* Charlie would no longer need to sleep with oxygen and he *might* live a few years longer than expected. In a panic, Sandra and Chuck spent many weekends over the next year

2 - Quality of Life

traveling around the country looking for a better place. But after all the frantic activity, they decided to stay put, in a community where Charlie was included in school and in community activities, surrounded by friends who loved him. These relationships and experiences truly represented a great quality of life for Charlie. The physician's "prediction" that Charlie might live a few years longer paled in comparison to the richness of Charlie's life in the here and now.

Twenty years ago, I was told my baby son with cerebral palsy needed therapies and specialized interventions to improve his quality of life. It didn't take long to realize, however, that these services *interfered* with the real quality of life for Benjamin and our entire family! The hectic schedule of therapies and interventions stole precious moments—days, weeks, and years—of family time, as well as time for Benjamin to simply be a baby, and more. I was a slow learner then and, sheep-like, I followed the orders of experts until six-year-old Benjamin tearfully expressed his feelings: "Going to therapy doesn't make me feel like a regular person." That was the end of his therapy career. We found more natural ways of providing the assistance he needed in inclusive settings, which automatically improved his *real* quality of life.

Ed Roberts and others with disabilities taught me that Benjamin didn't have to walk to have a good life, but he *did* need independent mobility (a power wheelchair) *and* a good education so he could be employed as an adult. Thus, pulling him out of the general ed classroom for PT and OT would have been counterproductive, since he'd then miss academics. Similarly, a person doesn't need to talk to have a good life, but she *does* need effective communication (a device, cards, etc.) and a good education. And a "good" education may or may not include reading, for example. Some people may never be able to read, but that doesn't mean they can't *learn*—using books on tape, computers, DVDs, experiential activities,

and more. Children with disabilities also need to learn how to live in the Real World—not the "special" environments of Disability World—if we expect them to be successful in the Real World as adults.

Trying to improve a person's quality of life (as defined by functional skills) can have profoundly negative effects on the person's real quality of life (being in control of your life, relationships, and experiences). While parents chase cures and treatments for a child with a disability, family relationships, ordinary (and precious) experiences, sanity, and contentment evaporate. When educators insist on "helping" a child in a segregated special ed resource room, what opportunities is the child missing in a general ed classroom? And when providers require adults with disabilities to spend years in "readiness" activities, real quality of life—a Real Life—remains out of reach.

It seems that the usual therapies, interventions, and services provided to "improve" quality of life (functional skills) are *focused on the future*. In my family's situation, therapists worked diligently on many "get

ready" skills that were intended to help my son sit up, walk, eat, etc., *at some point in the future*. But very little attention was paid to what was important for him (or our family) *at that moment in time!* The same is true for millions of children and adults with disabilities. While we focus on tomorrow, next month, or next year, or on the next prerequisite skill, today slips away—opportunities, joys, and experiences are lost—"getting ready" for tomorrow.

Is *your* quality of life determined primarily by what your body or brain can do (now or in the future), or is it a result of the choices you make day in and day out, the experiences you have from morning until night, and the family and friends who surround you at home, work, and play? What will it take to ensure children and adults with disabilities have the same opportunities to control their own destinies, including the ordinary experiences and relationships needed to create their own quality of life?

"For your own good" is a persuasive argument that will eventually make man agree to his own destruction.

Janet Frame