WHAT'S HAPPENING TODAY? WHAT'S REALLY IMPORTANT?

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

Enormous efforts (and millions of dollars) are expended on behalf of people with disabilities. Therapies, special programs, writing goals, and more are the tip of the "helping" iceberg. Those who provide the help (parents, teachers, service providers, health care staff, etc.) have the very best of intentions, but do our efforts help children and adults live the lives they want *today,* and are we focused on *what's really important* to them? And shouldn't these fundamental questions guide everything we do?

In her middle school special ed classroom, 12-year-old Sarah is expected to spend hours learning to tie her shoes. Is this really an important skill? Will it help Sarah get a job one day? No. Are there any shoe-tying jobs? No! If there were, *and* if shoe-tying was important to Sarah, then by all means, let's spend time on this. Otherwise, we should forget about it. Our time, *and Sarah's,* should be spent on ensuring Sarah is a successful sixth-grader, *today*—in academics, in extra-curricular activities, and other areas *of real importance to Sarah.* And Sarah can wear slip-ons, clogs, or boots, or she can wear her lace-up shoes *untied* like all the other sixth-graders!

Tom, a senior in high school, is still pulled out of class by the occupational therapist for handwriting. (And this has been going on since kindergarten.) Is he studying to be a calligrapher? No! So why is time wasted on this? If Tom can sign his name the way a physician does, that's good enough; the rest of Tom's work can be done on the computer. And aren't computer skills more likely to enhance Tom's success in post-secondary education and/or employment than handwriting?

Forty-year-old Becky still has an annual goal of "combing her hair." As a result of her disability, Becky can't reach her arms over her head, so why is she expected to learn to comb her hair? Because it's considered an important life-skill, even though Becky has never been too interested in her hair! So why can't people in Becky's life provide *real* help by ensuring her hair is cut, styled, and/or permed so it requires minimal care?

While Sarah, Tom, Becky, and countless others are being forced to spend time on things that are *not* important to them, what are they missing out on—*what important things are they <u>not</u> doing?* Much of their time, unfortunately, is spent on "get ready" skills. But why aren't we focused on ensuring they're living the lives they want *right now*—not tomorrow or next year or whenever it is that they're deemed "ready"?

That nasty Disability Double Standard rears its ugly head again, for people who do *not* have disabilities routinely do things before they're "ready." They also do not spend days, months, or years on "activities" that are not important to them—activities which are supposed to get them "ready" for something, at some point in the future. No, they live their lives in the present—today!

When you left your parents' home, did *they* think you were ready for the responsibilities of adulthood? Probably not, but you left home anyway and struggled through, learning from experience. When you got married, you did so on your own timetable, even if waiting—for more maturity or more financial stability—might have made for a wiser decision. When you bought your first home or had your first child, were you really ready? Think of all the other experiences you've had that, if tested, you wouldn't have passed the "readiness test." People *without* disabilities routinely do what's really important to them, *today*—they don't always wait until they're ready, and throughout their lives, they learn from these experiences, including (perhaps especially) their failures. What will it take for us to recognize and value what's really important to people with disabilities, and ensure those things are happening now?

My son, Benjamin, received massive amounts of physical and occupational therapies during the first six years of his life. (He chose to "resign" from his "therapy career" at age six and we found more natural ways of helping him do what was important to him.) The therapists were wonderful people, dedicated to the children they served. But in thinking back to those six years of my young son's life, I realized most of the therapists' time was spent on "treatments" that *might* enable Benjamin to "do" this or that at *some point in the distant future.* There was very little done to help my son live a wonderful life *at that moment in time.*

Time is really the only capital that any human being has and the only thing he can't afford to lose.
Thomas Edison

For example, the therapists worked from the conventional wisdom that a person can't do "C" unless he's first mastered steps "A" and "B" (this "sequential model" is embraced by many parents and professionals). Long after Benjamin had learned to walk in a walker, therapists continued to work on crawling! Why would he want to crawl when he was three years old? He wanted to walk like other kids his age. To add insult to injury, the physical therapist was against my son even having a walker (but I insisted and was supported by the ortho doc). The therapist believed Benjamin "wasn't ready" for a walker—he hadn't learned to crawl, so surely he couldn't walk (and to her, walking in a walker wasn't "real" walking)!

Hours, days, weeks, months, and years were spent on other "developmental" skills (based on the able-bodied standard), like the pincer grasp, sitting up, and more. At that time, I didn't always recognize what was really important—I was still influenced by the "readiness model" and other myths of conventional wisdom. I did question *some* things, but I didn't have the wisdom, for example, to tell therapists to forget the pincer grasp. The therapist was correct: Benjamin could not pick up a dime with his thumb and forefinger. He could, however, pick up a toy with his whole fist, so why was the pincer grasp so important?

Back then, I didn't know to insist that they spend their time on—*and teach me about*—strategies and/or activities to ensure that Benjamin, for example, could live a successful life as a three-year-old. Luckily, we had an older child who had *been* a three-year-old), and Benjamin was included in an ordinary preschool, instead of attending a segregated special ed preschool, so I knew what was important to be a successful three-year-old. But this seemed to be unimportant to and/or absent from the consciousness of therapists.

Ironically (or perhaps logically), it was adults with disabilities who encouraged us to make sure Benjamin had what he needed to live a Real Life. They helped us learn, for example, how important it was for Benjamin to have a power chair so he could be more in control of his life. Why didn't therapists or medical professionals see the importance of assistive technology in his life?

Our decision to focus on what was important to Benjamin, regardless of what experts dictated, and to make sure Benjamin had what he needed (assistive technology, supports, accommodations, etc.) at any given moment in time, was liberating and joyous! No longer did we spend one moment worrying about Benjamin not meeting this goal or that—his life wasn't "on hold" until he reached this developmental milestone or mastered that functional skill. Our family (especially Benjamin) began really living again!

Today, Benjamin probably still could not pass the tests for the pincer grasp, sitting up, or crawling, but he's a successful college student! So what's really important for the Big Picture?

Situations similar to what we experienced almost two decades ago are still happening today. While great progress has been made in some areas in the disability arena, it seems many people are still stuck in old ways of thinking, such as:

- Trying to fix/change people through therapies and interventions (Medical Model);
- Embracing the Sequential/Developmental Model (a person can't do "C" until he's mastered "A" and "B");
- Holding people hostage to the "Able-Bodied Standard" and the "Readiness Model."

If we operate from these or similar tenets of today's conventional wisdom, our well-intentioned efforts to "help" people with disabilities may actually "retard" their development. Let's go back to 12-year-old Sarah and 40-year-old Becky for a moment.

Sarah has been in segregated special ed classrooms from the time she was three. Educators determined she couldn't learn traditional academics in general ed classrooms, so she's only been exposed to life-skills in special ed classrooms. Early on, her parents had high hopes, but they reluctantly accepted the low expectations suggested by educators. Shoe-tying and the attainment of other life-skills goals have been part of Sarah's IEP (Individualized Education Program) for years. At age 12, Sarah certainly is behind academically, not because of her disability, but because she's *never been given the opportunity* to learn reading, writing, and math! Her growth and development—educationally, socially, and more—have been retarded by segregated environments and low expectations.

Many know that "learned helplessness" is an unintended consequence of doing too much for people. "Learned retardation" can also be an unintended consequence of having low expectations for people and limiting their opportunities to learn and grow in inclusive environments. (See the article "Beware the Retarding Environment.") If the trajectory of 12-year-old Sarah's life isn't changed, she will follow in the footsteps of 40-year-old Becky, and will end up in a group home and a sheltered workshop, and shoe-tying may remain an important goal!

Education is not preparation for life. Education is life itself.
John Dewey

Many of us have heard about "failure to thrive," in which a child has a condition that prevents the child from physically growing. But this condition is also applied to children who are raised in orphanages or other impoverished environments, where their development is stunted because they're deprived of normal social interactions and ordinary childhood experiences. Interestingly, according to a variety of websites, the condition is also being seen in older adults who have lost interest in living. Is it possible that children and adults with disabilities may exhibit a type of "failure to thrive"—stunted emotional, social, and/or intellectual development—as a result of the impoverished environments inherent in many segregated settings, where low expectations and the lack of ordinary experiences and relationships are the norm?

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Yes, many people are born with conditions that delay or interfere with their cognitive, behavioral, and/or physical development. These delays, however, can be *increased* by "retarding environments" or they can be *decreased* by the abundance of opportunities and relationships available in ordinary and inclusive environments.

The wants and needs of individuals with disabilities are no different from people without disabilities. Children with disabilities want and need to: grow and play and learn and have friends; "do it themselves;" make mistakes and learn from them; enjoy the grade-to-grade progression in school; blow their allowance on (what we call) junk; spend the night at a friend's house; giggle and tell secrets; go to birthday parties; dream big dreams for their future (and have their parents and teachers support those dreams); and so much more. Adults with disabilities want and need to: reach adulthood and move on with their lives (into their own places); work at a good job and/or contribute in a meaningful way; enjoy relationships (friends, romance, and more); take responsibility; experience the changes in life from youth to middle age and beyond; and so much more. (And, yes, there are some adults with developmental disabilities who say they don't need or want to work since they can get by on government assistance, but they've been programmed to believe that by their parents, teachers, or others with influence over their lives.) Finally, people with disabilities don't want to be forced to spend their lives doing activities intended to fix or change them, and they certainly don't want to spend their lives waiting—as life passes them by—for someone to judge them as finally being "ready."

So how do we make the change? How do we ensure people with disabilities are doing *what's important to them right now?* Begin by critically examining your actions (or lack thereof) in the life of a person with a disability, and what role you might have played in preventing the person from living the life of his or her choice—today! It's hard to correct a problem if we first don't acknowledge there *is* a problem!

Next, we can recognize the value of assistive technology, supports, and/or modifications children or adults with disabilities might need in order to do what's important to them right now—and then we must do whatever it takes to put these in place. A power wheelchair, communication device, a digital watch, calculator, computer, electric toothbrush, books on tape, environmental changes, peer support, behavior supports, and/or a host of other things can be considered. These can not only open the door to success, but can also eliminate the need for therapies, special programs, or interventions focused on fixing the person. If Tommy gets a power wheelchair, there's no need for years of physical therapy focused on Tommy's legs! If Marcie has a digital watch, there's no need to spend weeks and months on "time-telling."

The next step is to do what it takes to ensure a person with a disability is *engaged* in the direction of his or her life. With children, this is relatively easy; most are still full of boundless hope; with adults, it can be more difficult because many have been brainwashed into hopelessness (more in a moment). We can talk to children about what's important to them, what they want to learn, what they want to do, etc.

Does Tommy want to play sports and/or join Scouts? Does Kristy want to take a ballet class and/or try her hand at babysitting? Does Brian want a power wheelchair *now* so he can get from point A to B in the most efficient manner possible, so he can play or work or do other things of interest, or does he want to continue with physical therapy in order to (maybe one day) learn how to walk? Does Marianne want a communication device or communication cards, so she can tell people what she wants and needs *today*; or would she rather go to speech therapy indefinitely in the hope that she'll one day learn to talk? Does James want to stay in the special ed classroom (life-skills) or would he like to be in the 5th grade, with whatever supports he needs? Does Sonja want to be pulled out for therapies at school, or would she rather have the therapists in the general ed classroom helping her with real-life skills, or would she rather end school-based therapy altogether? Whose life is it, anyway?

We can ask adults with disabilities similar questions, relative to their personal situations, but we may need to first convince them that this isn't all a joke—that they really will be heard. Many have years of experience of no one listening to them.

Our focus on what's really important to a person needs to be coupled with a sense of urgency—the same urgency we experience in our own lives to get things done. We don't put our lives on hold, waiting until we're "ready;" and we try not to waste a day! We can no longer ask people with disabilities to wait—to spend even one more day that's wasted on unimportant activities. Their lives are spent "getting ready," and day after day is wasted.

Parents: if therapists or other specialists are not helping your child live a wonderful life today—*right now*—then they're more of a hindrance than a help, for not only are they not really helping, they're also wasting days of your child's (and your family's) life. You and your child could be doing wonderful things instead of spending the day "doing therapy." And what's happening in school every day? If you don't know, better find out—quickly. Spend the day in your child's classroom. Are teachers helping your child be successful *today?*

If you work with adults with disabilities, are you helping the person live a great life right now? Or is your focus on the person mastering this skill or that, *one of these days?*

The strategies described in this article can enable us to help a person with *"being"* (being a six-year-old or being a 25-year-old or being a student or being a worker), instead of *"doing"* (acquiring functional skills, range of motion, etc., etc., etc.). They can then take their rightful places in society, for too many children and adults are invisible; they're not part of the mainstream in our schools, our communities, or our workplaces. This is not only a tragedy for them, it's a tragedy for us. We need them in our lives. We need their gifts, talents, and experiences. We need to learn from them, even as they learn from us.

Diversity makes our society stronger. Let's do what it takes to ensure our society benefits from the diversity that people with disabilities bring to the table. We need their contributions *today.*