The Power of the Environment

Does a person who has been labeled with a disability *always* have a disability? Perhaps the answer is "yes" if considered narrowly from a legal perspective (e.g., being considered a person with a disability under the Americans with Disabilities Act, meeting the criteria for special education and/or other services, etc.). These situations are, in essence, theoretical. A governing body *decides* what a disability "is" (and the definition can be changed at any time) for the purpose of ensuring civil rights, entitlements, and/or other benefits for those who meet the criteria.

In *practice,* however, whether a person *always* has a disability is more a consequence of the environment: physical, social, attitudinal, and more. For example, in our home and other environments where our son, Benjamin, has the assistive technology, supports, and accommodations he needs, his disabilities (cerebral palsy, low vision, and more) become irrelevant.

In his power wheelchair, Benjamin can get from point A to point B on his own. Using his laptop computer, with everything on the screen enlarged, he can read and learn, and can also write his school papers (since he can't write with pen and paper). Other devices, some high-tech and some low-tech, along with a variety of supports and accommodations, enable him to be more self-reliant and live the life of his dreams.

On the other hand, if Benjamin *doesn't* have the needed assistive technology, supports, and accommodations, he may be helpless and dependent and experience difficulties in learning and other activities. His disabilities go from irrelevant to "severe-to-profound," and a bright future turns dim. It's all about the environment.

> Whether a person [with a disability can be] gainfully employed or work as an independent producer depends less on his medical condition than on his educational level, motivation for work, and the personal, economic, and political opportunities open to him. Nevertheless, the concepts of disease and disability are typically yoked together, with medical certification for disability focused on what the subject cannot do because of his medical impairment, rather than on what he can do in spite of it.
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> *Thomas Szasz, MD*

As Thomas Szasz describes (see box), the focus is on what a person "cannot do because of his medical impairment, rather than on what he can do in spite of it." In most IEP meetings (as well as "I" meetings for adults with disabilities), scant attention is paid to what changes in the environment (physical, social, attitudinal, etc.) can or should be made to promote successful outcomes.

Parents of children with disabilities have shared their experiences when meeting with educators to write their child's IEP (Individualized Education Plan). Time after time, parents report the following: "I don't know who they're talking about at the IEP meeting; the child they're describing isn't the child I know." Too many professionals focus on what the child cannot do; parents focus on what their child *can* do at home and in other environments.

During a recent presentation, one mother shared her thoughts after my discussion about the importance of the environment: "In school, my son has Asperger's Syndrome; but at home, he doesn't. And I can't get the people at the school to understand this." What was the difference between home and school? The environment.

We don't need to try to change individuals with disabilities—to intervene with therapies, treatments, etc.—in order to "fix" them or make them "normal." They're not broken and don't need to be fixed. We need to, instead, *change the environment,* and we can do that! People *without* disabilities change their environments all the time, by purchasing the latest gadget to make our lives better, increase productivity, etc. We ask for and receive support from a variety of others (paid and non-paid). If we're not so good at this-or-that, we find someone to assist us. We arrange

our homes and offices to meet our individual needs and so much more. In addition, most of us spend time (at work, play, home, etc.) with others based on our shared *interests,* not our perceived *deficits.* This is in sharp contrast to the routine practice of "placing" people with disabilities in environments with others who have similar "problems."

Back to the words of Thomas Szasz, do we create environments that will enhance a person's "educational level, motivation for work, and personal, economic, and political opportunities"? Let's think about the different aspects of the environment.

Physical: Is the environment physically accessible? If not, what needs to be changed? Think in terms of architectural issues. In addition, does a person with a disability have the assistive technology devices needed to participate fully (at home, school, work, recreation, worship, and other places)? Assistive technology devices can make an enormous difference, but mobility and/or communication devices are two of the most important that can enhance people's full participation, increase self-reliance, and ensure personal autonomy and safety.

Social: Does the environment welcome all who want to participate? Do educational, recreational, religious, and/or other ordinary places expect people with and without disabilities to participate together, or have they created "special" (segregated) parallel "programs" for people with disabilities? When needed, are behavioral supports in place? People *without* disabilities use behavioral supports—they're called cigarettes, Starbuck's, chocolate, shopping, and/or whatever else gets you through the day.

Attitudinal: Individual and collective attitudes (pity, prejudice, ignorance, low expectations, etc.) can generate negative consequences for people with disabilities, and they're actually at the *root* of physical and social environmental barriers. We've encountered many buildings that are inaccessible for a person who uses a wheelchair. So we've politely approached the store personnel, stating that our son would like to come in and spend money on their merchandise, but he can't get in the door. Too many times we've been told, "We don't have a ramp because we don't have

> **Don't let what you cannot do interfere with what you can do.**
> *John Wooden*

people like that come to our store." No kidding—they can't come in because there is no ramp! Circular logic is at work.

A special education director shared a dilemma about a middle-school boy who had "behavior problems." The solution? Assign the student a one-on-one aide (a middle-aged woman) who would sit with the boy in classes, walk him from class to class, and so on. This solution was supposed to generate improvements in the boy's behavior, but his behavior deteriorated. So the school decided to double-down and assign a *second* one-on-one aide. (Guess that makes it two-on-one.) The special ed director couldn't see that by changing the social environment this way, they made the problem worse. The fault, they believed, was the boy's. To me (and others), it was apparent that the boy was embarrassed and felt stigmatized, was made to feel (and look) incompetent, and more. Before deciding to use "guards," did the school try other environmental changes that could have a positive impact on the student and his behavior?

A woman who is described as "totally blind since birth" was presenting at a disability-related conference in a hotel meeting room—a room with no windows. During the middle of her presentation, and unknown to the audience, she had the hotel staff turn off all the lights—it was now pitch black. Some people panicked, thinking something awful was happening. The presenter rapped on the podium and asked everyone to be seated and be quiet—it was still pitch black. Then she asked, *"Now* who has a disability? I'm fine, and so are a few others in the room—we don't need the lights. Electric lights are assistive technology devices for people who have sight." Badda-bing, badda-boom!

We hope children with disabilities will learn to speak, right? So why do we put children who are not yet talking in a class with others who are also not talking? It makes no sense. They need to be in an environment with other children who talk!

A group home supervisor believed there was no way a woman with an emotional-behavioral disorder (EBD) could ever be successful in the community. The woman threw food, screamed, and had other "inappropriate behaviors." When asked what type of environment the woman was in, the reply was,

"She lives in an EBD group home." Hmmmm.... what might happen when people with EBD labels are forced to live together? Think they might learn from each other's behavior in that environment?

A 35-year-old woman with a disability has a part-time, sub-minimum wage job stocking shelves and cleaning in a small store. She's had a job coach there for two years. Does *anyone* need a job coach for that long? Is it possible the woman is in the wrong job—the wrong environment?

A 50-year-old man with Down syndrome has spent his life in sheltered (segregated) environments, where low expectations have been the norm. He has the same IQ as a child with Down syndrome, but the two are as different as night and day. The child has always been included, and has learned academics in general education classrooms. Everyone has high expectations for him. Unlike the grown man, the boy's diagnosis has not been a barrier to his success. They are both products of their environments.

All of us are products of our environments. A carpenter could not build anything without a hammer and nails. A surgeon would have poor outcomes if she had to operate in a dirty room, if she didn't have the support of qualified assistance, and if she had to do her job under unrealistic time constraints. I could not write this article without the technology most of us take for granted, and without a quiet time and place to get the job done. Without the appropriate physical, social, and attitudinal environments, you would not enjoy success either. Keep thinking of other examples.

At the same time, if you're a drug addict or an alcoholic, and you want to change, you can't keep hanging out with other addicts. You have to get out of addicting environments and into sober living. If we want people with disabilities to be more successful, they need to be in ordinary, inclusive environments where they can shine and succeed.

So long as we focus on a person's medical diagnosis and what she cannot do, we'll remain *ignorant and oblivious* to the power of the environment. Slotting people with disabilities into the environments of

"special programs" has been the traditional approach since the time of institutions hundreds of years ago. Incredibly, the practice continues today, in schools, recreational and religious activities, adult services, and more. This practice has led to poor outcomes for children and adults with disabilities, as evidenced by off-the-chart unemployment and lifetimes of impoverishment, under-education, and invisibility in the mainstream of American life.

The first step in the process of change is an attitude adjustment: to realize a medical diagnosis is not the defining characteristic of the person (just as my medical diagnoses do not define me, and yours don't define you). We need to focus on what the person *can* do, instead of what he *can't,* and we need to be fully committed to determining what changes in the environment can "level the playing field" and enhance the person's abilities and achievements in all areas of life.

Providing assistive technology devices, supports, and/or accommodations should not be considered "special treatment" (people *without* disabilities couldn't get along without what they need). Nor—in our still rich society—should financial barriers stand in the way. There's always a way to go over, under, or through those barriers if we're determined and creative.

Every person is *born* included. Inclusion is the default position; a person will be included unless someone in authority decides to "place" the person into a segregated, special, and unnatural environment. Who has the moral authority to rob a person of the right to remain in the inclusive environment he's born into?

William Hazlitt says, "Great thoughts reduced to practice become great acts." A positive change in our attitudes will result in a positive change in our actions that, in turn, will generate positive changes in the lives of people with disabilities.

All of us have the *power* to change our attitudes—*our mental environments.* Do we have the *will* to change this most important part of our anatomy?