

Exposure and Experience

From the www.disabilityisnatural.com E-Newsletter by Kathie Snow

How often do we presume a child or adult with a disability is incapable, incompetent, unable to learn, and so forth? Have we considered that perhaps the person has had no exposure to or experience with the situation?

“Sara” talked to me about her son with a disability, “Tommy,” describing how far behind he was compared to his brother and other children (without disabilities). During our conversation, it became apparent that Tommy had not had the same *opportunities* as his brother or other children. Because Tommy spent his life in segregated, self-contained environments at school and in special sports activities, he did not have *exposure to and experience with* education in a general ed classroom, as well as ordinary age-appropriate and inclusive community, social, or recreational activities. Tommy hadn’t learned how to: get along in the real world, make decisions, be responsible, make friends, be safe, or a myriad of other typical skills that are *routine* for children *without* disabilities.

This lack of exposure and experience during Tommy’s childhood will, in general, cause him to be ill-equipped for a successful life as an adult. He will have learned only how to survive in self-contained, segregated environments. And instead of looking at what *we* did or didn’t do, we (Tommy’s family members, teachers, professionals, and/or others in his life) effectively “blame the victim:” Tommy can’t (do-this-or-that) because he has (type of disability).

Consider the example of orphanages in some Eastern European countries where very young children were left untended by staff. Because of the lack of human interaction, the children were diagnosed with “failure to thrive.” They were denied the normal opportunities that promote growth and development; they were products of their environment. *And all of us are products of our environment.*

The philosopher Ivan Illich wrote, “Most learning is not the result of instruction. It is rather the result of unhampered participation in a meaningful setting.” Think about it: “unhampered participation” and “meaningful setting”— do those descriptors fit what happens to most children or adults with developmental disabilities? Not really. Most don’t experience “unhampered participation” in any setting; their lives are circumscribed by plans, rules, schedules, consequences, helpers, etc. You may believe that a child being in a self-contained classroom or an adult in a day program/workshop *does* represent a “meaningful setting.” But in comparison to what? If all you’ve ever had is vanilla ice cream, you think it’s the best! You might feel differently after visiting a 31 Flavors ice cream shop.

The opportunities available to children and adults with disabilities are not limited by *their diagnoses*, but by *our attitudes and actions*. We put limits on them because we’ve put limits on our imaginations! We’re hampered by the status quo, conventional wisdom, standard practices, etc.; we tend to do what’s always been done. We’re stuck.

And the consequences to the children and adults with disabilities in our lives are incalculable.

Let’s think about choices. When I was a child, I had a list of “what I wanted to be” when I grew up. But I’ve never done any of those things! Why? Because as I matured, I had experiences that taught me about jobs I didn’t even know existed. Back in the late 1970s, I was a secretary at a local TV station. It was an incredibly exciting new world of producers and camera operators and film editors and technical directors of the local news shows. And, boy-oh-boy, I thought being a director would be a fun job! I asked my boss about the possibility. He thought it was a ridiculous idea and was very discouraging. First, he told me, I was “a girl” (I was 26) and females didn’t do

He displayed the physical characteristics of Down syndrome so just one look at his face and everyone knew there was no point in sending the boy to school. It’s true he was a slow learner but that might have been because nobody ever tried to teach him anything.

*Colin Cotterill in
Disco for the Departed*

2 - Exposure and Experience

jobs “like that.” Second, I couldn’t be a director until I could operate a studio camera, adjust lights, build sets, and much more. But I was determined and I applied for the next “studio tech” opening. I got the job and took a cut in my already low pay. Then I worked hard, learned much, and *did* become a director (one of the first female directors in the state of Texas I was later told).

It took exposure to and experience with TV production to make it happen. Growing up, neither myself or my family, nor anyone who knew me, ever considered I’d enjoy a career in television. It was possible because my parents and teachers didn’t put limits on me; I was free to try this-and-that—to explore and make choices about my life. My situation is not unique; most adults (without disabilities) have enjoyed a lifetime of making choices that have led to exposure to and experience with new situations.

Some of the choices we made didn’t turn out as well as we thought, right? “It seemed like a good idea at the time...” And most of us learned a great deal from our screw-ups; our failures are usually more instructive than our successes. Children and adults with disabilities need the same opportunities to explore, discover, succeed, fail, etc.—to learn!

What will it take for us to ensure children and adults with developmental disabilities are participating in ordinary experiences that promote personal growth? What are the barriers? The answers are flip sides of the same coin.

First, focus on the person’s strengths and abilities, not the diagnosis or “problems.” Then your mind will be open to possibilities. If, for example, you feel that, “Helena will never be able to (fill-in-the-blank)...” *You’re right!* Helena will *not* be successful—not because she has a disability but because of *your attitude!* If, however, you see her abilities and strengths (and ensure others also focus on those traits), and if you

also ponder *how* Helena can be successful, you’ll figure out what supports, accommodations, assistive technology, etc., she needs to make it work. Add in some big dollops of patience as necessary!

Next, minimize your fears and maximize your hopes. We may inadvertently put limits on people with disabilities because of our fears: the person might fail or embarrass himself or us; others might not like or understand the person; it’s asking “too much” for others to include/welcome a person with a disability; and the list goes on and on. We cannot allow *our* fears/emotions to limit another’s opportunities. Embrace hope and trust in the kindness of strangers.

Finally, expect success and support failure. If your first efforts don’t work, try again! Learn from the experience

and value the lessons learned; commiserate with the person instead of criticizing (and share some of *your* failures). Brainstorm how or what to do differently next time.

Throughout, we need to be listening to the person with a disability. What is the person interested in doing? What would be relevant and meaningful to him/her? Be on the look-out for opportunities and share your ideas with the person.

Your enthusiasm and excitement will rub off on the person. And there’s no doubt you’ll run into a “no” sometimes, but don’t take it personally—this is not about you! See a “no” as a positive: the person is speaking up and self-advocating! (You want your wishes to be respected when you say “no”—treat others the way you want to be treated.) Open the door to opportunities; exposure and experience can enrich a person’s life forever!

See these related articles:

“Environment, Environment, Environment”
www.disabilityisnatural.com/environment.html

“Permission to Fail...and Succeed”
www.disabilityisnatural.com/permission-to-fail.html

**You are what you learn...
A person changes at a
fundamental level as he or
she merges with a particular
field of knowledge. If you
don’t like who you are, you
have the option of learning
until you become someone
else. There’s almost nothing
you can’t learn your way out
of. Life is like a jail with an
unlocked, heavy door. You’re
free the minute you realize the
door will open if you simply
lean into it.**

Scott Adams