Inclusion: The Natural State

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

In the United States and many other democracies, every person is born included! This is not a time or place of European serfs, American slaves, or a caste system where your position in the social hierarchy— including whether you’re included or segregated—is preordained. In our society, inclusion is not a right that must be earned; it is the natural state.

That’s the ideal we operate from. But it’s not the reality for many children and adults with disabilities who are subjected to an archaic paradigm: at the moment a disability condition is diagnosed, they’re consigned to segregation and second-class citizenship! Like serfs, slaves, or “untouchables” in other times or cultures, they’re placed at the bottom of the social hierarchy, controlled by others, and segregated in “special” places with their “own kind.” Opportunities for an ordinary life, education, and employment are limited (a substandard education automatically limits employment). It can be nearly impossible to climb out of the gutter of special, segregated programs.

Unlike other times or cultures where segregation was automatic, in our society we have to do an extraordinary amount of work to ensure segregation and second-class citizenship. And our efforts take place at both systemic and individual levels.

Systemically, we’ve created special programs/services which are often located in special places, and staffed by specialized experts: early intervention, special education, special sports, special church programs, special college programs, special habilitation services, special vocational assistance, and more. In the process, we inadvertently created a duplication of services. For example, our communities already have schools, sports activities, employment services, and so much more!

Historically, however, these ordinary services and activities were not thought to be appropriate for people with disabilities. For the last 200 years or so, we’ve operated from the paradigm that people who happen to have conditions we call disabilities needed to be cured/treated and protected from a cruel society, while simultaneously protecting society from the “menace” of the “defectives,” so institutions (the ultimate in special, segregated places) were created.

Fast-forward to the deinstitutionalization efforts begun in the 1960s: if the “inmates” of institutions were to be released, “community-based” services must be created to meet their “special needs.” The special services mindset was entrenched (along with a burgeoning new industry which employs millions). But think about it: at the time—and even today—which is easier, better, and more cost-effective: to modify the existing services in a community to meet the needs of all, or to create a new and separate set of services (which result in segregation)?

Beyond the moral and ethical issues involved, how can we continue to fund segregated programs with government funds (tax dollars), when federal and state laws (ADA, IDEA, Rehab Act, and more) mandate non-discrimination, least restrictive environment, and other basic tenets which promote inclusion, equal access, and more? (There is a huge disconnect between what our laws say and how government funds are spent, which needs further examination in another article.) So, systemically, we’ve worked very hard and spent billions of dollars on programs and services that (intentionally or unintentionally) promote segregation and erase the natural state of inclusion.

At the level of the individual, we also expend great amounts of energy. We diagnose, assess, observe, and test, often using multi-disciplinary teams of experts. Then we study, quantify, and qualify the data; write reports; share those reports; and assess some more, to determine the prognosis, treatment, intervention, etc. Then we have meetings (IFSPs, IEPs, IPPs, I-cetera) to formalize, sanction, and justify our decision to segregate, such as placing a child in a life-skills class or an adult in a group home or day program. Then we treat, intervene, therapize, supervise, manage, and more. Oh, how much work it all takes! And everyone—teachers, providers, parents, and others—complains: too much work, too much
time, too much stress, and too many rules and regulations to follow.

Of course, throughout all these systemic and individual processes, no one ever utters the words: “Let’s figure out how to segregate this person and consign him to a second-class citizenship.” Instead, we talk in terms of “helping.” Regardless of our words or our intent, the outcome is the same: the loss of the natural state of inclusion, and with it, the loss of opportunities: to live a real life; to grow up like your brothers and sisters; to be a friend, neighbor, lover, spouse, softball player, bookworm, exuberant child, determined student, enthusiastic employee, selfless volunteer, or whatever you want to be. The loss of inclusion is like a living death: the devastating loss of ordinary, but precious, hopes and dreams.

But what can happen when we embrace, internalize, and base our actions on the fact that every person is born included, and that no one has the right to impose segregation and second-class citizenship on another? No one has the right to deliver the unspoken and soul-crushing message of today’s conventional wisdom: “Because you have a disability, you are not okay the way you are. But we will try to make you ‘better’ with treatments and interventions and services. And if you work hard enough, you may—one day—earn your way out of segregation.” Substitute “Because you have been found guilty of a crime...” and it’s easy to see that many people with disabilities are treated as if they’re convicted criminals.

No parent, therapist, or service provider has the right to replace the joyous freedom of childhood with a regimen of treatments; no teacher has the right to exclude a child with a disability and rob him of the opportunities to learn and grow from ordinary classroom and social experiences; no human services system has the right to incarcerate an adult with a disability in a congregate setting.

Inclusion is the natural state; anything else is an artificial environment. What could happen if our highest guiding principle was to ensure the natural state of inclusion continues throughout a person’s life? This would require us to hold inclusion as a higher value than services and interventions geared to “help” the person. In many quarters today, inclusion isn’t even on the radar screen; we focus on services—and segregation continues.

Yes, many people with disabilities may need more or different assistance, than those without disabilities, but as previously mentioned, our communities are rich with generic (and inclusive) services. So why can’t a person with a disability be helped to access the “regular” employment services offered in his state? Why can’t an adult with a disability be helped to live in the place of her choice, with roommates of her choice, and with the supports she needs (natural and/or system supports)? Why can’t a child with a disability be in general ed classrooms? Why can’t a child take a ballet or karate class or do other fun activities (with consultation from a therapist, if necessary), instead of receiving therapy for years? Why don’t we ensure people with disabilities have the accommodations, supports, and assistive technology they may need to be successful in inclusive environments?

Those who have chosen to stay on the path of inclusion have learned that it can be done—this is not pie-in-the-sky thinking! And, yes, it can sometimes take a little more work or time or negotiation, but the effort is worth it, and it’s much less effort, in total, than the extraordinary amount of work to segregate!

We may think our actions are driven by, and can be justified by, the type or level of disability. But it’s never about a person’s disability; it’s always about our attitudes, perceptions, and beliefs—our values. And where does inclusion fit in our hierarchy of values?

Look into the face of a person with a disability and acknowledge that he or she was born included, then question how the segregation and second-class citizenship of that person—along with the unmitigated and tragic loss of inclusion, opportunities, and hopes and dreams—can be justified. Keep looking, and imagine the awesome possibilities when inclusion is your highest operating principle.